

The Lived Experiences of Hospital for Parents of Children Commenced on Invasive Long-term Ventilation

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Abstract

Recent years have seen a significant increase in the number of ventilator-dependent children being discharged from the hospital. There is a wealth of literature describing the issues surrounding the complex discharge process required for these children however there has been limited exploration of the experiences of parents during their child's admission to hospital. Interpretive phenomenology based on Heideggerian research philosophy was used to explore the lived experiences of hospital for parents of children commenced on invasive long-term ventilation (I-LTV). Purposive sampling was utilised to select parents of children who had been cared for at one NHS hospital trust. Eight in-depth, unstructured qualitative interviews involving sixteen parents (eight couples) were conducted over a six month period during 2014 to gather data about the parent's recollections of the time spent with their child in hospital. Most children were cared for on both the paediatric intensive care (PIC) and high dependency units (HDU) with the majority having been discharged from hospital at the time of the interviews. All interviews were transcribed verbatim, and analysed using a modified van Manen (1990) approach. Thematic analysis provided an insight in to the lived world of the parents caring for their technology-dependent child, with two overarching concepts of uncertainty and transitions characterising the parents' journeys. The findings revealed multiple transitions in a world of complexity and uncertainty with four main themes emerging from the data; 1) Going in to the Unknown, 2) This wasn't what we wanted, 3) Safer at Home, and 4) Clawing every little bit back. Parents were required to develop coping strategies to deal with the transitions and uncertainties experienced and establish new roles and identities as they became experts in caring for their technology-dependent child. As a result of the findings a new framework combining the concepts of uncertainty and transitions was derived identifying areas for consideration including: health-illness, psycho-social, situational and developmental transitions together with existential, biographical, environmental, relational and temporal uncertainties. Strategies for facilitating coping and adaptation towards healthier outcomes were identified and a strong argument emerged for the

development of more effective management of transitions and uncertainty delivered within an environment more conducive to family-centred care.

Dedication

I dedicate this thesis to the parents and children who through their participation have enabled me to complete this study. But more importantly who by sharing their experiences have allowed me to gain a better understanding of the complex world in which we expect them to accept and survive without question. In allowing me the privilege of hearing about their experiences and then translating them in to this academic piece of work has provided me with a unique opportunity not only to listen to what they have said but essentially act upon their words and begin to change the way in which we care for the future children and their families who will also benefit from this work.

I would also like to dedicate this thesis to the parents of TS as it was as a result of their experiences in hospital that took me down the road of exploring the experiences of other parents whose children had been commenced on invasive long-term ventilation and also finally I wish to dedicate this work to the memory of JS who sadly died in 2015.

The findings presented in this thesis will be reported in an executive summary which will be sent to all the participants along with a letter of thanks for taking the time to take part in the study and allowing me to use their descriptions of their time spent in hospital with their child. It is also anticipated that the findings will be presented at national and international respiratory meetings, and may be published in peer reviewed nursing and medical journals.

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Contents

Abstract.....	1
Dedication	3
Acknowledgements	4
Contents.....	5
Structure of Thesis.....	8
Abbreviations used in the study.....	10
Definitions of Long-term Ventilation used in the study.....	10
1 Introduction to the Study.....	11
1.1 Background to the study.....	12
1.2 Evolution of Research Interest.....	14
1.3 Aims and Objectives of the Study	15
2 Review of the Literature	16
2.1 Introduction	16
2.2 Literature Search for Children commenced on I-LTV.....	17
2.2.1 Prevalence of LTV	18
2.2.2 Reasons for LTV	19
2.2.3 Decision-Making in I-LTV	21
2.2.4 Outcomes	22
2.2.5 Bed occupancy and Length of Stay.....	24
2.2.6 Discharge Planning - From Hospital to Home.....	25
2.2.7 Safety of I-LTV.....	27
2.2.8 Parental Experiences of Caring for a Child on I-LTV in Hospital	28
3 Research Methodology	31
3.1 Introduction	31
3.2 Fields of Philosophy	32
3.3 Phenomenology	35
3.3.1 Philosophical Origins of Phenomenology	35
3.3.2 Husserlian Phenomenology.....	36
3.3.2.1 Intentionality	37
3.3.2.2 Bracketing (Epoché) & Reduction.....	37
3.3.3 Heideggerian Phenomenology (Hermeneutics)	39
3.3.4 Descriptive or Interpretive Phenomenology?	41
3.3.4.1 Max van Manen	43
3.3.4.2 Levels of Reduction.....	45
3.3.5 Limitations of Interpretive Phenomenology	47
3.4 Research Method.....	49
3.4.1 Research and Clinical Governance	49
3.4.2 Study Approval	50
3.4.3 Participant Sample	50
3.4.4 Participant Recruitment	51
3.4.5 Confidentiality & Anonymity	53
3.4.6 Ethical Considerations	54
3.4.7 Data Collection	55
3.4.8 Pilot Interview	58
3.4.9 Main Data Collection	59
3.4.10 Joint Interviews	59
3.4.11 Data Analysis.....	61
3.4.11.1 Transcription.....	63

3.4.11.2	Thematic Analysis	64
3.4.12	Validity, Trustworthiness and Rigour	67
3.4.13	Summary	70
4	Study Findings	72
4.1	Main Themes.....	72
4.1.1	Main Theme 1: 'Going in to the Unknown'	74
4.1.1.1	Uncharted Territory	75
4.1.1.2	Mixed messages	87
4.1.2	Main Theme 2: 'This wasn't what we wanted'	98
4.1.2.1	Uncertain Futures.....	98
4.1.2.2	Information and Signposting	104
4.1.3	Main Theme 3: 'Safer at Home'.....	107
4.1.3.1	Vigilance	108
4.1.3.2	Involuntary Separation	114
4.1.4	Main Theme 4: 'Clawing every little bit back'	119
4.1.4.1	Uncertain Parenting.....	119
4.1.4.2	Extraordinary parenting.....	127
4.2	Conclusions	136
5	Discussion Chapter.....	140
5.1	Introduction	140
5.2	Study Limitations	141
5.3	Theoretical Links to Uncertainty and Transitions	143
5.3.1	Concept of Uncertainty	143
5.3.2	Uncertainty related to Health	145
5.3.3	Concept of Transitions.....	150
5.3.4	Transitions in Health.....	151
5.4	Parental Experiences of Uncertainty	157
5.4.1	Antecedents of Parental Uncertainty.....	157
5.4.2	Appraisal of Uncertainty.....	165
5.4.3	Consequences of Uncertainty	166
5.4.4	Coping with Uncertainty and Adaption.....	167
5.4.5	Management of Uncertainty	171
5.4.6	Outcomes of Uncertainty	172
5.5	Parental Experiences of Transitions.....	173
5.5.1	Nature of Transitions.....	173
5.5.2	Health-Illness Transition.....	174
5.5.3	Psycho-social Transitions.....	177
5.5.4	Situational Transitions.....	180
5.5.5	Developmental transitions	183
5.5.6	Facilitators and Inhibitors.....	184
5.5.7	Patterns of response – Process and Outcomes.....	188
5.6	Links between Transitions and Uncertainty	192
5.7	Implications for Clinical Practice.....	196
5.8	Recommendations	201
5.9	Suggestions for further research	205
5.10	Conclusion.....	207
6	References.....	213
7	Appendices.....	242
7.1	Appendix 1: NRES Approval	242
7.2	Appendix 2: NRES Approval Confirmation	247
7.3	Appendix 3: NHS Trust R & D Approval.....	249

7.4	Appendix 4: DMU Ethics Approval	251
7.5	Appendix 5: DMU Sponsor Confirmation	252
7.6	Appendix 6: Research Working Agreement (DMU/NHS Trust)	253
7.7	Appendix 7: Research Invitation Letter.....	256
7.8	Appendix 8: Participant Information Sheet	257
7.9	Appendix 9: Participant Consent Form	260
7.10	Appendix 10: Interview Schedule	261
7.11	Appendix 11: Example of Thematic Map Analysis of Interview 001.....	262
7.12	Appendix 12: Example of Thematic Summary: Theme 1 'Going into the Unknown'	263
7.13	Appendix 13: Summary of Thematic Analysis.....	264
8	Bibliography	265

Structure of Thesis

The following summary provides an overview of the structure of the thesis and highlights the content of each chapter.

Chapter 1: Provides an introduction to the thesis and the aims and objectives of the research study to explore the lived experiences of hospital for parents of children commenced on invasive long-term ventilation (I-LTV).

Chapter 2: Presents the literature review and considers the existing published work concerning the overall context of children commenced on I-LTV with a focus on publications regarding the experiences of parents caring for their ventilator-dependent child in hospital. In keeping with the chosen research methodology an initial limited literature review was undertaken based on the decision that a contemporaneous approach to review further literature would be commenced as themes emerged from the findings.

Chapter 3: Presents the chosen research methodology based on the philosophical approach of phenomenology. The chapter presents an overview of descriptive and interpretive phenomenology and provides an account of the research methods used and the data analysis approach adopted for this study. Based on Heidegger's interpretive phenomenology the study used a modified hermeneutic approach influenced by van Manen to explore the 'lived experience' of the participants.

Chapter 4: Presents the findings of the study and is separated into four sections one for each of the four main themes emerging from the data. In-vivo quotes used to capture the main thematic findings were use as headings for each section. The overall findings of the parents' experiences reveal what appear to be two overarching concepts of 'uncertainty' and 'transitions'.

Chapter 5: Offers a discussion on the findings of the study and considers the two overarching concepts of 'uncertainty' and 'transitions'. The chapter reviews the main theoretical frameworks supporting the two concepts and identifies areas of

congruence with Mishel's (1988) Uncertainty in Illness Theory and Meleis's *et al.* (2000) Transitions Theory. Additional findings relating to the concepts were not recognised by either Mishel's or Meleis *et al.*'s theories, consequently a new model based on the parents' lived experiences in this study was developed. This new model provides a unique contribution to knowledge and offers a basis for healthcare professionals to consider and reflect upon the parents' lived experiences. Additionally it aims to facilitate recognition of the parents' needs during this period of uncertainty and transition. Finally the chapter presents the conclusions and recommendations of the study including the implications for clinical practice, education and research.

Abbreviations used in the study

DH:	Department of Health
ECMO:	Extracorporeal Membrane Oxygenation
ICU:	Intensive Care Unit
I-LTV:	Invasive Long-term ventilation
LTV:	Long-term ventilation
NICU:	Neonatal Intensive Care Unit
NIV:	Non-invasive ventilation
PICU:	Paediatric Intensive Care Unit

Definitions of Long-term Ventilation used in the study

LTV: Long-term ventilation includes anyone who when medically stable continues to need a mechanical aid for breathing following a failure to wean, three months after the institution of ventilation

NIV: Non-invasive ventilation involves mechanical ventilatory support delivered via a nasal mask or face mask

I-LTV: Invasive long-term ventilation involves mechanical ventilatory support delivered via a tracheostomy

1 Introduction to the Study

The last fifteen years has seen a rapid expansion in the number of children requiring Long-term Ventilation (LTV) with an increasing number cared for at home (McDougall *et al.* 2013). Whilst most children require non-invasive ventilatory (NIV) support there are increasing numbers of children with more complex respiratory problems who are entirely dependent on invasive ventilatory support via a tracheostomy (I-LTV) (Wallis *et al.* 2011). In the past these children would have spent many months or years in the intensive care unit. However, as a result of medical advances and government policy emphasising community based care (Department of Health 2005a, 2010) it is now accepted that, once medically stable, the child should be cared for in the family home with support from community services (Kirk, 2001). When faced with this reality parents often endure a complex and difficult pathway whilst waiting for their technology-dependent child to be discharged from the hospital setting.

It is already known that the hospital to home pathway for this group of patients is fraught with frustration and delays for both the child and their families (Noyes *et al.* 2014). There is extensive literature documenting barriers, to and reasons for, delays to discharge; and recent years have seen the development of publications providing specific guidance on the discharge process for the professionals involved (Department of Health 2010 & 2016, Lewis & Noyes 2007, Noyes & Lewis 2005, NHS England Leicester & Lincolnshire Area Team 2013). These guidance documents provide suggested strategies to facilitate the discharge process and aim to streamline the pathway from hospital to home. They highlight where the barriers and delays to discharge usually occur thereby ensuring that there is transparency for all involved including the families. Moreover there is usually extensive discussion with the parents about providing intensive and highly technical care in the home, yet it is recognised that the extra physical and emotional burden is not always discussed at the time of the decision for the child to commence I-LTV (Wang & Barnard, 2004). In addition professionals have a reluctance to provide too much information at the outset in case they place extra distress and anxiety on to the families (Noyes 2000). Healthcare

professionals know these families can and often do come under enormous pressure (Davies & Carter 2013) therefore they need to ensure that the multi-disciplinary team involved in caring for these children support the individual needs of the parents and families.

The findings from this research study will highlight the complex world the parents live in caring for their technology-dependent child in hospital. Improving care for this vulnerable group of children and their families requires greater understanding from those directly involved in supporting them through this difficult time of transition and beyond. By providing further understanding of the experiences encountered by parents it is hoped that professionals will have greater understandings of the issues faced by these families and thereby enhance current practice which will help to improve the complex discharge process and journey home.

1.1 Background to the study

Long-term ventilation has been defined in the paediatric population as:

“any child who, when medically stable continues to require a mechanical aid for breathing, after an acknowledged failure to wean or a slow wean three months after the institution of ventilation.” (Jardine & Wallis 1998)

Children require LTV for a variety of medical conditions including chronic respiratory failure due to underlying clinical conditions. The ventilatory support can be delivered via a non-invasive interface using either a face or nasal mask which is known as non-invasive ventilation (NIV). Or it can be delivered via a tracheostomy which is known as invasive long-term-ventilation (I-LTV).

Having a child commenced on invasive long-term ventilation (I-LTV) is a major life-changing event and involves the child undergoing elective surgery for a tracheostomy. A tracheostomy is an artificial airway that facilitates support of breathing and is a safer and more effective option when mechanical ventilation is required for more than a few days (Pandian 2013). Tracheostomies may be used to facilitate long-term positive

pressure ventilation, but may also be required when a child has an upper airway obstruction caused by congenital malformation or has a neuromuscular condition to assist with more effective airway clearance (Glader & Palfrey 2009). For the conscious patient it is also a more comfortable option as it permits eating and drinking when conditions allow, without breathing tubes positioned through the nose or mouth. However, tracheostomies have a higher level of risk in terms of airway patency as they are at risk of occlusion due to thickened secretions or foreign objects blocking the lumen of the tube. There is also the potential for the tube to become dislodged or displaced and airway occlusion for whatever reason can be life threatening. Furthermore due to the anatomical positioning of the tracheostomy tube situated below the vocal chords, when patients talk or cry there is little or no sound to alert professionals and carers to the fact they are distressed or seeking attention. Consequently babies and young children who are dependent on I-LTV require continuous care and observation over a 24-hour period due to the associated risks with the technology.

The number of children on LTV is growing with a greater than 600% increase in children affected over the ten years between 1998 and 2008 (Wallis *et al.* 2011). This increase in numbers is mainly due to improved perinatal survival (Hefner & Tsai 2013), advances in medical technology and the improvement of home care respiratory equipment (Benneyworth *et al.* 2011, Edwards & Nixon 2013, Wallis *et al.* 2011). In the past children commenced on I-LTV would have remained in hospital, mainly on PICU because of their complex medical needs. However, due to improvements in home-care technology and a government drive towards care being provided in the home (DH 2004) there are increasing numbers of technology dependent children being cared for in the home environment (Murphy 2008). Furthermore there is increased pressure to reduce hospital length of stay for these children with the recognition that because of increasing numbers of children being commenced on I-LTV, hospitals could no longer accommodate these patients on a long-term basis (Wang & Barnard 2004). As children occupy beds for many months it reduces PICU capacity meaning other children

requiring critical care services have to be transferred to units further away from home and elective procedures having to be cancelled due to local bed shortages (NHS England, 2015 E07/S/c). In addition, there is an increasing awareness that the hospital environment is unsuitable for prolonged stays (Benneyworth *et al.* 2011, Cancelinha *et al.* 2015, Carnevale *et al.* 2006) and, as Noyes (2002 p.3) reported, living in hospital for prolonged periods has a 'profound and negative impact on children and their families'.

1.2 Evolution of Research Interest

Having worked as a paediatric respiratory nurse for over twenty years caring for children with a wide range of acute and chronic respiratory conditions in both the hospital and community settings I was familiar with children being commenced on LTV. Recently due to the advances in medical technology and the interests of the paediatric respiratory clinicians at the tertiary care hospital where I worked I became increasingly involved in the clinical care and management of this complex group of technology dependent children. Although the numbers of children on I-LTV were initially relatively small the implications of this growing population were significant for all concerned including the professionals looking after the children, the commissioners funding the healthcare and the parents who were expected to take care of their children.

In 2010, in addition to my clinical role, I began working as the LTV co-ordinator for Specialised Commissioning in the East Midlands. This post was developed to support and improve the discharge process for the children commenced on I-LTV, following recognition that these children were remaining in hospital for significantly longer than they needed to; mainly due to delays and barriers in the discharge process. The combination of this commissioning support post working alongside my role as a nurse consultant opened my eyes to the expectations and demands placed on the parents of these children from both a commissioner and provider perspective. As my experience and understanding increased, so did my personal interest in exploring the experiences of the parents and the multiple challenges they faced with their children being commenced on I-LTV. Essentially it was because of my concern for the psychological and emotional well-being of these parents and the influence and control the clinicians

had on them that I decided to undertake my doctoral thesis exploring the experiences of parents whose children following admission to hospital and due to their critical illness were commenced on I-LTV.

1.3 Aims and Objectives of the Study

The aim of the study was to explore the 'lived experience' of parents throughout their time spent in hospital caring for their ventilator-dependent child. Using qualitative methodology based on the philosophical tenets of hermeneutic phenomenology the objective was to gather knowledge and information on both the positive and negative aspects of the parent's experiences; from the child's initial admission, commencement onto I-LTV, through to the eventual discharge home. It is anticipated that the findings from the study guided by the research question of 'what are the 'lived experiences' of hospital for parents of children commenced on invasive long term ventilation?' will build on existing knowledge and provide further information on the complexities of caring for this group of technology-dependent children. The findings will also provide a basis for further discussion and the development of information and support aimed at improving the care and management of these highly dependent children and their families, ultimately improving the experiences for future parents encountered as they care for their child. It is anticipated that better understanding of the lived experiences of parents caring for a child on I-LTV in hospital, will also benefit professionals involved in providing and commissioning care for these children.

This first chapter has introduced the overall intentions of the research, provided a background to the subject of children requiring I-LTV and described the aims and objectives of the study. The next chapter provides a review of the literature associated with children initiated on I-LTV and appraises the current work exploring the experiences of parents caring for their I-LTV child whilst in hospital.

2 Review of the Literature

2.1 Introduction

The overall purpose of a literature review is to explore existing work and assemble a view on what knowledge currently exists with regard to the topic of investigation (Polit *et al.* 2001). By gathering information any gaps or inconsistencies in the literature can be determined and areas for research to contribute to the body of knowledge can be ascertained (Denscombe 2008). Accordingly the literature review lays the foundation for the study and helps to establish whether the research will produce an original contribution, supplementary to existing knowledge in keeping with the aims of a doctoral study (Silverman 2010).

The approach and parameters of the literature review vary in accordance with the research method used (Grbich 1999). Although an in-depth literature review prior to data collection is considered essential for quantitative research there are conflicting ideas regarding its use in qualitative research (Polit *et al.* 2001). Some suggest qualitative researchers should not consult any literature prior to the study as it may influence the conceptualisation of phenomena being studied (Wojnar & Swanson 2007), whereas others regard a view of existing work as helpful to guide the direction of the study (Silverman 2010). Importantly, as Koch (1995) recommends, nurse researchers should thoroughly appraise the philosophical underpinnings of their chosen methodology prior to undertaking the review as this will influence the approach taken. In research based on the philosophical principles of phenomenology there is a belief that literature reviews may be vehicles for potential bias (Matua & Van Der Wal 2015, Munhall 1994, Wojnar & Swanson 2007). Therefore based on the chosen research philosophy and methodology of interpretive phenomenology (discussed in chapter 3) the decision was taken to perform a limited literature review prior to data collection and analysis based on the understanding that in-depth and systematic reviews could influence exploration, scrutiny and interpretation of the findings. Thus in accordance with the philosophical tenets of this study a limited literature review was performed based on the following aims:

- a) Overall assessment of literature concerning children commenced on invasive long-term ventilation (I-LTV)
- b) Identification of current literature exploring the parent's experiences of caring for a child on I-LTV whilst in hospital

The findings of the review relating to children commenced on I-LTV and the parents' experiences of caring for their child whilst in hospital will be presented in the following section.

2.2 Literature Search for Children commenced on I-LTV

Using an electronic search of databases (CINAHL, EBSCO Host, SCOPUS, PUBMED) a literature search was conducted using 'key' words of "long-term ventila*", long term ventila*", "technology-dependent", "ventilator dependent", "hospital", "child*", "parent*" and "parent* experiences". The search was limited to publications written in English between 1990 and 2014 based on the following. Firstly, although children have been managed on mechanical ventilation in hospital for many years, prior to 1990 the incidence of children being discharged from hospital on I-LTV was relatively low. Secondly in recognition that the social and political context of the research is highly relevant in phenomenology particularly with regard to the analysis and interpretation of the findings (Heidegger 1962, McConnell-Henry *et al.* 2009b, van Manen 1990) it was considered appropriate to limit the review of literature and evidence pertinent to the research in the current context.

As Polit *et al.* (2001) acknowledge it is rare for electronic literature searches to identify all pertinent studies therefore in addition to using the electronic search of databases, additional references cited in the associated literature were identified, sought and skim read for relevance. Furthermore due to a limited awareness of the research area and my clinical and commissioning roles I had established a working knowledge of key publications and documents relating to LTV.

Using existing knowledge and the combined search strategy identified above the search revealed extensive literature on the subject of children requiring long-term

ventilation. Most of the literature broadly focussed on the subject areas of prevalence, outcomes, hospitalisation, discharge planning, and the impact of caring for a technology dependent child in the home. Literature surrounding the parental experiences of caring for a child on I-LTV whilst in hospital was also intentionally sought, although it was acknowledged that this would potentially bring bias as well as increased awareness to the research phenomena being studied, diminishing openness to the data as it emerged (Munhall 1994). Despite not wanting to explicitly review the issues faced by parents during their time in hospital, it was important to establish if this was an area of research that had been previously explored. From the review undertaken some of the literature inevitably included aspects of the parent's experiences in hospital whilst preparing to take their child home, nevertheless it appeared that very few studies had specifically focused on exploring the lived experience of parents at the time of their child being initiated on to I-LTV.

A summary of the literature reviewed is presented in a structure based on the patient pathway and begins with a review of prevalence and reasons for initiating LTV including the common diagnoses and decision-making involved. It then considers bed occupancy plus length of stay, discharge planning including barriers to discharge, outcomes and safety of I-LTV and finally literature specifically exploring the parent's experiences of their child's time in hospital.

2.2.1 Prevalence of LTV

The last three decades have seen a significant increase in the numbers of children being commenced on LTV with the plan for them to be discharged home on this supportive technology (Benneyworth *et al.* 2011). Beginning in the late 1970s advances in ventilator technology, and a drive and acceptance for these children to be looked after at home has seen significant increases in the numbers of technology dependent children being discharged from hospital (Goodwin *et al.* 2011, Graham 2013, Jardine *et al.* 1999, Wallis *et al.* 2011). The dramatic increase in numbers can be seen from Robinson's (1990) early study of ventilator dependency in the UK in which 24 children were identified as being ventilator-dependent with only nine of them being cared for

at home. This is compared to later national surveys estimating a total of 141 children in 1998 (Jardine *et al.* 1999) and 933 in 2008 (Wallis *et al.* 2011) representing more than a 600% increase in children on LTV in the ten year period.

It is difficult to determine the exact number of children who are dependent on LTV due to the lack of reliable data collection (Murphy 2008) and to date there is no national database in the UK. Yet other studies have identified between a 10-fold (McDougall *et al.* 2013) and 30-fold increase (Goodwin *et al.* 2011) in prevalence over the last 15 – 20 years. Similar trends in the numbers of children on LTV particularly over the last two decades can be seen in other countries such as Canada (Amin *et al.* 2015, McDougall *et al.* 2013), the USA (Benneyworth *et al.* 2011, Divo *et al.* 2010, Downes & Parra 2000), Australasia (Edwards & Nixon 2013, Tibballs *et al.* 2010), Thailand (Preutthipan *et al.* 2014) and European countries (Cancelinha *et al.* 2015, Marchese *et al.* 2008, Paulides *et al.* 2012, Racca *et al.* 2011).

2.2.2 Reasons for LTV

There are a wide variety of medical reasons and diagnoses associated with the need for LTV (McDougall *et al.* 2013). In general LTV is used as treatment option for patients with chronic respiratory failure arising primarily from chronic pulmonary disorders, ventilatory muscle weakness and hypoventilation syndromes (Edwards *et al.* 2012). However, there are a number of additional conditions and although not an exhaustive list the main diagnostic categories include:

- Neuromuscular disease e.g. Spinal Muscular Atrophy (SMA) & Duchene Muscular Dystrophy (DMD)
- Congenital Central Hypoventilation Syndrome (CCHS)
- Congenital Diaphragmatic Hernia
- Spinal cord injury
- Airway abnormality e.g. Bronchomalacia
- Complex cardiac disease
- Chronic Lung Disease e.g. Broncho-pulmonary Dysplasia (BPD)

Some children will require LTV on a permanent basis such as those with a spinal cord injury whereas a significant proportion of children will require temporary ventilatory support until their condition improves with physical growth or evolution of the disease. LTV can be delivered non-invasively via a facial or nasal mask (NIV) or invasively via a tracheostomy (I-LTV). The decision pathway regarding which interface is used should involve active and open discussion with the lead clinicians, multidisciplinary team and parents (Halley 2012) and it is recommended that the discussion should occur prior to a tracheostomy being performed (Neupane *et al.* 2015). However, in reality, as Edwards *et al.* (2004) recognise, the decision regarding the need for acute ventilation is often made well before consideration of LTV and as Halley (2012) reports, in the case of critical illness, the tracheostomy is often performed prior to discussing the advantages and disadvantages of I-LTV as this is not seen as a possibility at the time. Therefore it is important to recognise that in some cases the tracheostomy is performed as a temporary measure, however, due to ongoing illness if the child is unsuccessful in weaning off the ventilator they consequently require ongoing ventilatory support which may become necessary for months or years (Jardine & Wallis 1998).

Furthermore there are some conditions that can cause significant ethical challenge in deciding the best course of action and treatment for the child and there is ongoing debate around the use of LTV in patients with degenerative conditions (Baird 2011, Dybvik *et al.* 2011, Kinali *et al.* 2006, Simonds 2005). However, the ethical debate relating to the decision to start I-LTV was not the focus for this study, therefore literature relating to this issue was not considered further. Nevertheless, notwithstanding the diagnosis and recognising the ethical debate regarding decisions being made in the best interest of the child, it is paramount that discussions regarding the initiation of LTV in children should involve the parents prior to commencement when at all possible. Yet there appears to be a lack of evidence to support discussion is taking place.

2.2.3 Decision-Making in I-LTV

As the requirement for I-LTV is often due to serious or complex conditions such as congenital cardiac abnormalities there is frequently uncertainty regarding outcomes and therefore decisions are regularly made in the critical stages of the illness at a time of high levels of stress and anxiety for the parents. Carnevale *et al.* (2006) argues there is significant controversy around the role and decision-making abilities of parents in situations where there are life and death decisions to be made with arguments for clinicians to be ultimately responsible for making the decision based on the premise that it places too much responsibility on the parent. Conversely there are strong arguments to support the role of parents in making these decisions with evidence suggesting this should be a shared responsibility (Birchley 2014, Madrigal *et al.* 2012, Pentz *et al.* 2012, Toebbe *et al.* 2013).

From the literature reviewed there appeared to be very little published information specifically regarding the commencement of children on I-LTV, although an abstract by Baird (2011) specifically addressed the issue. Baird's (2011) study based on a critical analysis of three case studies in PICU explored the "controversial issues" surrounding the initiation of long-term ventilation in children with chronic disease. This small study included the views of parents, clinicians and specialist teams involved in caring for the children and unsurprisingly failed to come to any conclusions regarding the legitimacy of LTV. However, it did highlight the vast ethical decision-making dilemma around initiation together with underlining the difficulty in determining who has the responsibility for making the decision.

Apart from Baird's (2011) study no other published papers could be found specifically concerning parents' involvement in decision-making around I-LTV with the majority of the literature focussing on decision-making in life and death situations particularly within the neonatal, critical care or oncology unit. The additional literature reviewed established that parents are often asked to participate in decision-making but concluded the decisions are not always informed and can cause great anxiety and distress (Anderson & Hall, 1995; Hallstrom *et al.* 2002; Eden & Callister, 2010). There

were also concerns about the degree of choice parents can exercise in the face of professional power (Hallstrom & Elander 2005, Kirk 2001, Wang & Barnard 2004). As the literature suggests, the decisions surrounding life-changing or life-limiting events such as initiating I-LTV are complex, especially when the outcomes are uncertain, and there appears to be very little information regarding this aspect of care in the current literature.

2.2.4 Outcomes

Longitudinal studies regarding outcomes of children commenced on LTV are also very limited (McDougall *et al.* 2013). However, a small number of studies have recently been published that have surveyed trends and outcomes in the last two decades (Amin *et al.* 2014, Edwards *et al.* 2010, Goodwin *et al.* 2011, McDougall *et al.* 2013, Tibballs *et al.* 2010, Wallis *et al.* 2011). Evidence suggests there is wide variability in the duration of LTV with McDougall *et al.* (2013) indicating a range between 0.3 – 12.1 years but this included both NIV and I-LTV. Information regarding the type of LTV is more forthcoming with studies revealing the use of NIV is more prevalent than I-LTV, with the UK study by Wallis *et al.* (2011) identifying 75% (n=704) of the 933 children were receiving NIV with only 22% (n=206) via a tracheostomy (I-LTV). The evidence suggests the total number of children receiving LTV has increased each year over the last 10 – 20 years with the increase attributed mainly to the use of NIV (Amin *et al.* 2014, Wallis *et al.* 2011). The number of children commenced on I-LTV over the same period has either remained static or fallen (Wallis *et al.* 2011) as NIV technologies have significantly enhanced respiratory management and are accepted as alternative treatment options for respiratory support (Goodwin *et al.* 2011). Nonetheless the use of I-LTV continues to play a significant role in the management of children with chronic respiratory failure with the majority of I-LTV being initiated in young children before they reach two years of age with a significant proportion commenced in the first year of the child's life (McDougall *et al.* 2013).

The preference for NIV or I-LTV is determined to some extent by the child's dependence on the ventilatory support and tolerance of the equipment although

advances in technology mean that patients are becoming more accepting of NIV masks used (Lofaso *et al.* 2014). There are also known complications arising from continuous use of mask ventilation such as skin breakdown and facial hypoplasia (Halley 2012) and therefore NIV may not be suitable if there is continuous dependence on the ventilator. The National Framework for Children and Young People's Continuing Care (DH 2010) defines the levels of ventilator-dependence as follows:

- High (Level 1): Is able to breathe unaided during the day but needs to go onto a ventilator for supportive ventilation. The ventilation can be discontinued for up to 24 hours without clinical harm.
- Severe (Level 2): Requires ventilation at night for very poor respiratory function; has respiratory drive and would survive accidental disconnection, but would be unwell and may require hospital support.
- Priority (Level 3): Includes those with no respiratory drive at all who are dependent on ventilation at all times, including those with no respiratory drive when asleep or unconscious who require ventilation and one-to-one support while asleep as disconnection would be fatal.

Many of the children requiring I-LTV have a Priority (Level 3) need due to their underlying condition although there are some children that can tolerate time off the ventilator. A significant number of children can eventually be weaned from the ventilator although may need to remain on it for years (McDougall *et al.* 2013, Wallis *et al.* 2011). The associated dependence on technology is an important aspect to consider with regard to mortality and morbidity and is covered later in section 2.2.7.

When children are initiated onto I-LTV it usually entails lengthy periods of hospitalisation for a number of reasons including stabilisation of the clinical condition, training of parents and carers in care of the technology and arranging homecare support. The related impact of these prolonged admissions has resulted in a number of papers focusing on this aspect of care provision from the perspective of the child,

family and hospital services which are summarised in the following section on bed occupancy and length of stay.

2.2.5 Bed occupancy and Length of Stay

The complexity of the clinical condition, training needs and necessary arrangements for homecare support often result in excessive lengths of hospital stay with evidence that ventilator-dependent children, especially those with the most complex needs, have occupied hospital beds for months, often years (Amin *et al.* 2014, Cejer 2007, DeWitt *et al.* 1993, Edwards *et al.* 2004, Fraser *et al.* 1998, Jardine & Wallis 1998, Lewis & Noyes 2007, Manhas & Mitchell 2012, Margolan *et al.* 2004, Murphy 2008, Noyes 2000, 2002, 2006, Paulides *et al.* 2012, Preutthipan *et al.* 2014, Smith & Hilliard 2011). Furthermore Fraser *et al.*'s (1998) study of 40 chronically ventilated children found that three quarters of the hospital admission was spent waiting for discharge with Edwards *et al.* (2004) estimating an average of 9.6 months extra time spent in hospital at considerable financial cost to the commissioner and emotional cost to the child and family.

Recent focus and drive towards reducing the length of stay has seen the average hospital stay decrease with the latest study by Amin *et al.* (2015) reporting a median length of stay of 162 days with an average of 97 days from the time of tracheostomy insertion. This is compared to Margolan *et al.*'s (2004) study of fifteen families reporting the median length of hospital stay as 513 days with one child remaining in hospital for 4 years. However, the Amin *et al.* (2015) study was located in Canada and evidence from the UK continues to report an average length of stay of between 210 - 270 days which has only improved marginally in the last twenty years (NHS England 2015). Despite the reduction in length of stay these children continue to occupy hospital beds for many months often without a medical need for them to be there (Noyes 2002, 2006, 2011). As a result these prolonged admissions have implications for the child, the family and the availability of hospitals to provide access to intensive care beds for other children (Noyes 2000). Fraser *et al.*'s (1997) study revealed that during the winter months in 1996 (January to March), 12% of PICU beds were occupied by

children dependent on ventilators. Similar figures have been measured nationally with the lack of PICU beds resulting in refusal of emergency admissions and cancelled elective surgical procedures (NHS England 2013, 2015). The overall impact on bed occupancy in PICU can be seen in Paulides *et al.* (2012) study which showed a total of 10,385 days could be attributed to just 67 children commenced on I-LTV between 1999 and 2009.

The financial implications of these prolonged hospital admissions have also been an area of focus as the cost of providing long-term complex care can be significantly more expensive in hospital than it is at home (Cockett 2012, Noyes *et al.* 2006). Although costs across the country vary considerably, the average costs of caring for a child on I-LTV at home ranges from £100,000 to £250,000 annually, compared to an annual cost of £750,000 in a children's ICU (Cockett, 2012). Therefore substantial health economy savings can be realised when the child is discharged to the home environment in addition to the significant gains in the child and family's emotional, physical and psycho-social health and wellbeing recognised when being cared for at home (Benneyworth *et al.* 2011, DeWitt *et al.* 1993, Edwards *et al.* 2004, Margolan *et al.* 2004, Noyes 2000, 2002). With this recognition there is a substantial body of literature relating to the discharge planning and process for this group of children.

2.2.6 Discharge Planning - From Hospital to Home

When children are commenced on I-LTV there is an inherent expectation from hospital staff that parents will take on the role of caring for their technology dependent child in preparation for them to be safely cared for at home (Kirk 2001). Parents are expected to become experts in providing technical clinical care assuming multiple roles including medical, palliative care provider, therapist, technician, educator and nurse (Graham 2013). Training the parents to safely care for the tracheostomy and ventilator takes between 6 weeks and 3 months and is usually provided by the hospital based staff prior to discharge but can include involvement of community based staff (Coad 2013, Lewis & Noyes 2007, Manhas & Mitchell 2012, Margolan *et al.* 2004, WMQRS 2013). According to Coad (2013) the type and level of LTV training for parents varies widely

across the UK and is dependent on location, caseloads and resources available. Coad (2013) also found comprehensive and consistent training systems to meet the training needs of families were lacking. However, there is agreement in the literature that a competency based approach to training is important with careful recording and documentation of competencies achieved due to the medico-legal complications and associated risks with caring for technology dependent children (Coad 2013, Jardine & Wallis 1998, Noyes & Lewis 2005).

In the past parents have reported insufficient knowledge and inadequate preparation for looking after their technology-dependent child (Wang & Barnard 2004) yet more recently an online survey conducted by the charity Breathe-On UK (2012) reported the majority of the 51 families whose child was discharged home on I-LTV felt physically (89%), emotionally (78%), psychologically (72%) and educationally (85%) prepared for the discharge by the time it occurred. However, many families reported a number of concerns around the process of discharge from the hospital with difficulties arising due to lack of communication and parents feeling 'ill-informed' about what would be required of them after the discharge.

Other aspects of discharge planning include making arrangements for the provision of equipment and homecare support based on the individual needs of the child. The National Framework for Children and Young People's Continuing Care (DH 2010) sets out the process for assessing, deciding and agreeing bespoke continuing care packages and includes a health needs assessment to guide the commissioning of services. Guidelines have also been developed to assist with the discharge process both nationally (Jardine & Wallis 1998, Noyes & Lewis 2005) and at a local level (NHS England, Leicestershire & Lincolnshire Area Team 2013). These guidelines have been developed as it has been recognised that there are multiple barriers to discharge which unnecessarily prolong the hospital stay (Edwards *et al.* 2004, Lewis & Noyes 2007, Noyes 2002). The resulting delays mainly arise due to inefficient communication, fragmented funding streams and poor interagency working (Halley 2012) however there can also be complex social issues and housing delays (Noyes 2002).

The majority of the literature concludes that a well-planned discharge is important to ensure the child is provided with safe and effective care in the home and that delays to discharge should be minimised (Margolan *et al.* 2004, Smith & Hilliard 2011). Furthermore it is acknowledged that supporting the parents through the acquisition of knowledge and skills through this difficult time is vital (Halley 2012, Murphy 2008, Smith *et al.* 2013). Nationally there continues to be a significant shift away from the hospital based model of care towards an ethos of healthcare being provided in the home (Coad 2013) and standards for the care of children requiring LTV have been published to help improve the quality of care and to ensure safe and effective services are delivered both in the hospital and at home (WMQRS 2013). This leads to consideration of the literature examining the important aspect of safety of the ventilator-dependent child at home.

2.2.7 Safety of I-LTV

A number of studies have examined the safety of I-LTV particularly when the children have been discharged from hospital (Edwards *et al.* 2010, Ramsey & Tsai 2009, Reiter *et al.* 2011, Schreiner *et al.* 1987, Tearl *et al.* 2006). Most of these studies concluded that the use of home ventilation is a safe alternative to hospital care. However, Schreiner *et al.* (1987) reported that six out of 30 deaths in the home were due to airway related accidents such as accidental decannulation, obstruction or disconnection from the ventilator. Ramsey & Tsai (2009) also reviewed mortality amongst invasively ventilated children being cared for at home in the USA and found that between 2002 and 2009, twenty-seven deaths occurred out of a total of 198 children. Of the 27 deaths, 24 were unanticipated with seven due to airway obstruction and two due to accidental decannulation. Edwards *et al.* (2010) also reviewed the causes of death in children on mechanical ventilation at home over a 22 year period and found that almost half the deaths were unexpected with 19% (n=9) tracheostomy-related although the exact nature of the event was not stated. However, Tibballs *et al.*'s (2010) study showed a much smaller incidence of accidental deaths with only two unexpected deaths occurring in children on I-LTV over a period spanning

from 1979 – 2008. Although much of the literature concludes that the use of home ventilation is a safe and effective alternative to hospital care these figures highlight the small but significant risk of accidental harm occurring which sadly can result in unexpected death. Therefore this helps to contextualise the responsibility and training parents and carers are required to undergo prior to taking their child home from hospital.

In addition to the literature reviewed above a number of studies have focused specifically on the needs and experiences of the parents in relation to their hospitalised ventilator-dependent child and are now considered.

2.2.8 Parental Experiences of Caring for a Child on I-LTV in Hospital

As the research aims for this study were to explore ‘the lived experiences of hospital for parents of children commenced on I-LTV’ it was important to review existing literature to ascertain whether research had already addressed this area of interest. All identified studies were read in accordance with the philosophical approach and methodology based on Heideggerian phenomenology discussed in Chapter 3 and are briefly summarised.

The literature search revealed a number of studies including the experiences of parents caring for children on I-LTV in hospital (Cejer 2007, Edwards *et al.* 2004, Kirk *et al.* 2005, Manhas & Mitchell 2012, Margolan *et al.* 2004, Noyes 1999a, Noyes *et al.* 1999, Noyes 2000, Noyes 2006, O’Brien 2001, Reeves *et al.* 2006, Samwell 2012, Wilson *et al.* 1998). However, none were found to exclusively explore the parents’ experiences of their time in hospital and many focused predominantly on the parents’ experiences of caring for their child at home (O’Brien 2001, Noyes 2006). Similarly Wilson *et al.* (1998) focused principally on the demands of caring for the ventilator-dependent child at home although the study findings reported some of the coping strategies and problem-solving skills employed by parents such as adjustments to daily routines when the child was admitted to hospital.

Despite most of the studies providing minimal information specifically on the experiences of parents within the hospital setting, they revealed important findings including recognition that prolonged stays in intensive care had a 'profound and negative impact' on the child and family (Noyes 2000 p.780). In addition studies also considered the required changes to the parents' roles and responsibilities and their experiences regarding the development of nursing skills and duties (Kirk *et al.* 2005, Manhas & Mitchell 2012, Noyes 2006), all of which would become important when considering the findings related to this doctoral study.

In addition many of these studies also focussed on the practical aspects of discharge planning as described in section 2.2.6 again revealing barriers to discharge such as inadequate communication, lack of coordination (Noyes *et al.* 1999, Noyes 2002 Samwell 2012) and the inability to organise and fund care in the community (Margolan *et al.* 2004, Noyes 2002, Reeves *et al.* 2006). Edwards *et al.* (2004) also highlighted what hurdles could be expected for healthcare practitioners including delays in finding adequate housing, recruitment and training of carers and social care issues.

Overall in accordance with Cejer's (2007) conclusions, the review of studies regarding parents' experiences highlighted a number of important findings including unmet needs of children on I-LTV and their families. However, Cejer's review also identified a lack of qualitative research regarding the parents' experiences in hospital and there appeared to be no duplication in the work that had been published and the research aims of this doctoral study. Therefore in agreement with Reeves *et al.* (2006) it was determined that further investigation was required to gain greater insight in to the experiences of parents which would then help to provide healthcare professionals' with a more in-depth understanding of families' experiences.

In summary the assessment of literature concerning children commenced on I-LTV provided a number of studies which were considered to be of importance. The literature presented a review of LTV prevalence, reasons for initiation of LTV, outcomes, bed occupancy & length of stay, discharge planning including barriers to

discharge and finally parent's experiences. When considering the literature specifically related to the parental experiences of their time in hospital, the search revealed limited information. Therefore I came to the conclusion that my research proposal based on the research question of 'What are the 'lived experiences' of hospital for parents of children commenced on invasive long term ventilation?' was valid and overall supported the need to undertake the study. Furthermore as Graham (2013) identified the numbers of children being discharged on I-LTV continues to increase and there has been little focus on the experiences of parents in hospital caring for their child. Therefore this is an area where more research is required because whilst it is recognised the numbers are small the needs of the parents and child are considerable.

The next chapter will now provide an overview of the research methodology chosen for the study and introduces the philosophical approach of phenomenology. The chapter also presents the methods used for data collection and concludes with a review of the study's trustworthiness and rigour.

3 Research Methodology

3.1 Introduction

Chapter two of this thesis presented a review of existing literature associated with children initiated on I-LTV and appraised a number of publications exploring the experiences of parents caring for their child on I-LTV whilst in hospital. The review was undertaken in preparation for conducting this doctoral research and supported the belief that further research was warranted as little research had focussed specifically on the parental experiences during this time.

Chapter three provides an overview of the research methodology chosen for this study based on the philosophical underpinnings of phenomenology and demonstrates how this philosophy influenced the methods and approach used for data collection and analysis. The chapter begins by summarising the fields of philosophy and discusses the two principal philosophical perspectives of descriptive & interpretive phenomenology developed from the findings of Husserl (1970) and Heidegger (1962). Further consideration is given to methodological approaches associated with phenomenology including the aspects of epoché (bracketing) and reduction (Heinonen 2015a) and outlines how these were applied in relation to the approach used. The chapter then describes the research methods used in completing the research study which were based on a combined approach of van Manen's (1990) six research activities and the hermeneutic principles of Gadamer (1976). The chapter will conclude with a review of the study's rigour and trustworthiness.

For the purpose of clarification, research methodology refers to the philosophical framework of the study and is the theory behind the method chosen whereas the method is the process and procedures employed to perform the research (van Manen 1990). Before further examination of the research methodology takes place the philosophical underpinnings of phenomenology are discussed as ultimately this relates to why this approach was chosen in the context of exploring the 'lived experiences' of hospital for the parents whose children had been commenced on I-LTV.

3.2 Fields of Philosophy

There are many views on the nature of reality and as Lincoln and Guba (2000) argue there is no single truth, yet in simplified terms there are two main views that dominate the literature. Polit *et al.* (2001) define these two broad perspectives on the nature of reality as arising from the positivist (scientific) and naturalistic paradigms and it is from these philosophical world views that researchers base their approaches in the acquisition of knowledge. Traditionally the positivist approach to gaining knowledge is based on the premise that there is a reality out there that can be objectively measured. Based on a Cartesian view of subjective-objective dualism (mind and body) the positivist approach lends itself to the research that is based on scientific methodology (Lincoln & Denzin 2000). Using ordered structure, empirical evidence and deductive processes in which the researcher is independent from those being researched it has become accepted by some as the basis for quantitative research. In contrast the naturalistic inquiry arose out of a countermovement to the positivist approach, exploring meaning and understanding it asserts that reality is subjective and constructed from within individual human experiences. Therefore multiple socially constructed interpretations of reality exist and the subjective views and experiences of those being researched are key to understanding the social world in which they live. It is through a constructionist approach of participant interpretations that we inductively generate theories from the research (Bryman 2001) and from a methodological perspective it serves the basis for a qualitative approach to research.

Although the terms quantitative and qualitative have become widely accepted as being helpful in research terminology to broadly distinguish between the research methodology used, both Oakley (1999) and Bryman (2001) believe this is unhelpful. They suggest there is considerably more to the distinction based upon the underlying epistemological and ontological orientations of the research. Nevertheless throughout the literature these terms are widely used and universally understood and have been generally accepted to determine the broad approach to the research inquiry. In keeping with this simplistic view of research this study used a qualitative approach to

explore the participant's 'lived experiences' based on the premise that a subjective interpretation would be best suited to uncovering the multiple realities of their experiences and appropriately aligned to my beliefs and values for conducting this research.

Within the literature associated with qualitative research there appear to be five distinct methodological approaches these being; grounded theory, ethnography, case studies, narrative and phenomenology (Creswell *et al.* 2006). Each approach is based on a different set of philosophical beliefs emerging from a variety of academic disciplines (Gelling 2015). The underpinning philosophical beliefs are important to enable understanding of which one of the five approaches is best suited to answer the research question although the methods employed in data collection and analysis may be similar.

Based on careful consideration of the research aims for this study the decision was taken to use an approach based on the philosophical underpinnings of phenomenology to answer the research question of 'What are the 'lived experiences' of hospital for parents of children commenced on invasive long term ventilation?' Although grounded theory was also considered to be of value and would have served as a credible alternative approach, the intention of the study was not to focus on generation of theory but to enhance understanding of the parents' experiences and in doing so raise awareness of the phenomenon experienced.

Table 1 provides an overview of the five approaches and illustrates the background, purpose, and the main methods for data collection and analysis.

Table 1: Summary of Main Qualitative Approaches

	Ethnography	Grounded Theory	Case Studies	Narrative Enquiry	Phenomenology
Purpose	To identify and explain cultural influence. Based on anthropology	To identify and explain social processes	In-depth exploration of a programme, event, activity, process or individual	Exploring the life of an individual which is then retold by the researcher	Understanding the essence of human experiences as it is lived by the participants
Background Discipline	Drawn from anthropology and sociology	Drawn from sociology	Drawn from psychology, law, political science, nursing and medicine	Drawn from humanities including anthropology, literature, history, psychology and sociology	Drawn from philosophy, psychology and education
Data Collection	Focus groups and participant observations and extended field work in the natural setting. Can include conversation, pictures, memos, documents	Semi-structured and narrative participant interviews and observations usually with small to medium sized groups with 20 – 60 individuals	Multiple sources including observation, Interviews, written documents and audio-visual material	Primarily uses interviews and documents	In-depth interviews with individuals or small groups
Data Analysis	Varied Symbols organised in to domains Generation of taxonomy to identify cultural themes and structure	Open coding: identify and organise units of data into categories and sub-categories. Axial and selective coding Discussion of theory and contrasts with existing literature	Categorisation and interpretation of the data in terms of common themes Synthesis into an overall portrait of the case	Analyses data from the stories and developing themes often using a chronology to develop a narrative about the individual's life	Gain a sense of the whole phenomenon reading and rereading transcripts and listening to interviews. Selecting of significant statements. Describe and interpret meaning. Synthesis of data
Outcomes	Rich description of culture and patterns of behaviour which may generate theory	To move beyond description and generate or discover theory 'grounded' in the data	Detailed analysis of one or more cases	Written narrative about the individual's life	Exhaustive descriptions and interpretations of meaning describing the 'essence' of the experience

3.3 Phenomenology

Phenomenology, described as both a philosophical movement and a research methodology (Flood 2010) was developed as an alternative to the scientific positivist enquiry (Denscombe 2008) which Mapp (2008) believed obstructed our understanding of the human experience and would not capture the true experiences of those being studied. Lester (1999 pg.1) described phenomenology as an approach “*based in a paradigm of personal knowledge and subjectivity*” in which the focus is to reveal meaning rather than to explain, predict or reveal facts through the generation of scientific knowledge (Flood 2010, Johnson 2004). The aim of phenomenology is to fully describe a ‘lived experience’ (Mapp 2008) and as Wojnar & Swanson (2007) considered, phenomenology is central to the ‘interpretive paradigm’.

3.3.1 Philosophical Origins of Phenomenology

Phenomenology, by definition is concerned with the study of ‘phenomena’ or the way we experience things and as such can only involve the inner subjectivity of those who have described the experience (Heidegger 1962, Husserl 1970, van Manen 1990). Polit *et al.* (2001 p212) describe phenomenology as having ‘disciplinary roots in both philosophy and psychology’, whilst Smith (2013) argues that phenomenology belongs to a distinct field on its own. Much of the literature supports that there are two main philosophical phenomenological approaches these being descriptive (eidetic) and interpretive (hermeneutic) with many texts using the terms interpretive and hermeneutic interchangeably (Benner 1994, Denscombe 2008, Flood 2010, McConnell-Henry *et al.* 2009a, Polit *et al.* 2001, Wojnar & Swanson 2007). Although the term phenomenology was used in philosophical texts as early as the 18th century (Earle 2010), the philosophical origins of phenomenology are acknowledged as developing in Europe through the German philosopher and mathematician Edmond Husserl (1859 – 1938) with further notable developments by Heidegger (1889 – 1976) who established the approach known as Hermeneutics. The philosophical perspective of phenomenology gained further strength through the writings of French philosophers Sartre and Merleau-Ponty and German philosopher Gadamer and has played a

dominant role in modern philosophy since World War 1 (Dowling, 2007). Despite Dowling (2007) stating there are many 'styles' of phenomenology, much of nursing research focuses on the two main philosophical approaches developed by Husserl (1970) & Heidegger (1962). Yet there are fundamental differences between these two approaches and as such it is important for the researcher to distinguish and clearly articulate which approach has been used for the purpose of the research (Dowling & Cooney 2012).

3.3.2 Husserlian Phenomenology

It is widely accepted that the principle founder of phenomenology was Edmund Husserl who wanted to create distance from the science of the natural world and introduced the concept of the 'life world' or 'lived experience' (Koch 1995). Husserl's phenomenology, characterised by some as 'transcendental' or descriptive phenomenology (McConnell-Henry *et al.* 2009b), is primarily concerned with the description of human experiences and concentrates on those that are untainted or unbiased and experienced directly without being analysed, or as Crotty (1996 pg. 95) describes the "*experience as it is before we have thought about it.*"

Husserl's philosophy was shaped by his teacher Franz Brentano who argued that there was a distinction between mind and body (Dowling and Cooney 2012). Based on this concept Brentano developed the theory of intentionality which Husserl later adopted. Although recognising empirical scientific research could not be used to study and understand all human experience (Mapp 2008), Husserl was driven to try and create an approach with scientific rigor which would be afforded similar esteem to the natural sciences. In doing so this would appear to afford aspects of objectivity more aligned to the natural science in which he based his early work (McConnell-Henry *et al.* 2009a). Therefore in order to expose the true 'essence' of the 'lived experience' Husserl considered it was essential for pre-conceived ideas and beliefs to be put aside and proposed using, 'bracketing' (epoché) and 'reduction' to achieve this. In addition he advocated 'intentionality' as one of the principle themes of phenomenology and

therefore to promote understanding these technical terms used within Husserl's phenomenology warrant further explanation.

3.3.2.1 Intentionality

Intentionality is a central concept in Husserl's phenomenology and can be defined as the conscious awareness directed towards an object or event (McIntyre & Smith 1989). For example, when you think you are always thinking of something or if you are angry you are always angry about something (Dowling and Cooney 2012). Likewise if you are conscious you are always conscious about something and hence the concept that phenomenology is the study of phenomena as they appear through the consciousness (Koch 1995). For Husserl the key to understanding human experience was intentionality and therefore his focus was to find the 'essence' or true meaning of the event or object and describe things as they appear (Dowling 2007, Koch 1995, Polit *et al.* 2001). He also argued that the world could only be known through the 'life world' as a pre-reflective experience, that which is immediately known to the consciousness and is free from bias and prejudice. Husserl therefore argued that to reach the 'essence' the investigator must discount any preconceptions or prejudgements, through 'bracketing' (epoché) or 'eidetic reduction' the concept of which is the hallmark of Husserlian phenomenological research (Converse 2012).

3.3.2.2 Bracketing (Epoché) & Reduction

There are many different views and opinions of exactly what bracketing and reduction are with evidence from the literature that much confusion surrounds the definition of these terms with Norlyk and Harder (2010) referring to 'bracketing', 'epoché' and 'reduction' as terms which have previously been used synonymously. However, Heinonen (2015a) offers a strong argument to suggest they are two separate entities with both 'epoché' (bracketing) and 'reduction' being essential to phenomenological research. In agreement Creswell (2007 p.235) refers to bracketing as the "*first step in 'phenomenological reduction'*". This raises an important discrepancy regarding the practice of using 'bracketing' and 'reduction' in phenomenological research as there appear to be contrasting views in how they should be used. This incongruity will be

revisited again later in the chapter when justifying the research approach taken for this study.

Bracketing

‘Bracketing’ or ‘epoché’ in descriptive phenomenology is defined as the cognitive process of putting aside one’s own beliefs (Speziale & Carpenter, 2007) with Heinonen (2015b) describing it as the freeing of oneself from assumptions. Husserl recommended that bracketing should occur before the study begins, during the collection of the data and revisited again during the analysis stage with Sorsa *et al.* (2015) recommending the researcher should focus entirely on the participants’ viewpoints during data collection and analysis.

Reduction

‘Reduction’ is defined by Heinonen (2015a p.36) as the technical term to describe the *“phenomenological device of bracketing”* and deals with *“returning to the original sources of individual’s experiences”*. According to van Manen (1990) one has to practice reduction to arrive at an essential understanding of something and this can only be done through reflection. Furthermore Heinonen (2015a) suggested that reduction can be practised on a number of levels depending on the methodology used. Munhall (2012 p.137) suggested researchers should *‘bracket’* personal knowledge by clearing their vision and assumptions from prior awareness and adopt a perspective of unknowing known as *‘decentering’*. This should be achieved by writing down beliefs, assumptions, preconceptions, and ideas about what the research would find, and in doing so clear the head of ‘noise’ and recognise what was already known. As Wojnar & Swanson (2007) contend it is the role of previous awareness and understanding that has led to some researchers using descriptive phenomenology to suggest that an in-depth literature review should be avoided prior to commencing the study as this prevents the research from being ‘contaminated’ by previous knowledge (Matua & Van Der Wal 2015).

One other notable aspect of descriptive phenomenology was that Husserl believed that neither time nor space were of importance regardless of the context (McConnell-Henry *et al.* 2009a) and espoused that only the consciousness of the individual constituted the truth of the situation and encouraged the context of the situation to be put aside.

In summary the descriptive phenomenology approach developed by Husserl requires the researcher to explore phenomenon affecting the 'lived experience' of the individual whilst setting aside preconceptions through the processes of bracketing and reduction to arrive at the true 'essence' of the experience. In contrast Heidegger, a student of Husserl, was more concerned with deriving meaning from the experience and moved away from purely describing to interpreting the phenomenon. Thus interpretive or hermeneutic phenomenology was developed as an alternative approach to phenomenological study.

3.3.3 Heideggerian Phenomenology (Hermeneutics)

The goal of phenomenological research according to Mapp (2008 p.308) is to "*fully describe a lived experience*". However, Heidegger fundamentally believed that to describe the experience was insufficient and sought to move beyond description to uncover, understand and interpret the human experience (Dowling and Cooney 2012, Polit *et al.* 2001, van Manen 1990). Heidegger further developed the work of Husserl and advocated the use of hermeneutics to not only understand but to interpret the human experience. The word hermeneutics as described by Annells (1996) is derived from the Greek word '*hermeneia*' which means interpretation, with the origins of hermeneutics relating back specifically to Hermes, who was a messenger to the Greek Gods (Ortiz 2009). Hermeneutics was first developed as a method in relation to the interpretation of biblical texts. Later in the nineteenth century it became used as a method to study the human sciences by Dilthey, who laid the foundations for Heidegger's work (Ortiz 2009). According to van Manen (1990 p.4) "*Hermeneutics describes how one interprets the 'texts' of life*".

Heidegger's hermeneutics differs from Husserl's descriptive phenomenology in a number of ways. According to Flood (2010) hermeneutics goes further than just providing description of central concepts and principles by looking for meanings. Flood (2010) also describes the difference between Husserlian and Heideggerian approaches as one that moves from an epistemological project to one focussing on ontology. Dowling (2007) concurs with this belief and describes Husserl's goals as epistemological in as much as phenomenology fundamentally claims to achieve knowledge, whereas Heidegger's philosophical stance had an ontological focus (McConnell-Henry *et al.* 2009a, Ortiz 2009) seeking to uncover the meaning of being or what he calls 'Being-in-the-world'. Heidegger uses the word '*Dasein*' to describe the context of a person's 'Being-in-the-world' (Annells 1996) and suggests that the world and the person are co-constructed (Dowling 2007, Koch 1995). This pivotal difference between descriptive and interpretive phenomenology relates to the concept of context being relevant to the research. In contrast to Husserl, Heidegger (1962) believed that context impacted significantly on an individual's experience and argued that humans are at all times immersed in the situation being studied. Accordingly Heideggerian phenomenology contends that the individual's cultural, social and historical context are fundamental and understanding cannot occur without consideration of these (Wojnar & Swanson, 2007).

Heidegger further postulated that to understand the person's situation in the world there should be a pre-understanding of the world or 'fore-structure' (Koch 1999), and fundamentally rejected the notion of bracketing (McConnell-Henry *et al.* 2009a). According to McConnell-Henry *et al.* (2009a) Heidegger considered that the only true way to conduct a Hermeneutic inquiry was for the inquirer to have some prior knowledge and understanding so that appropriate questions could be asked of the findings and then re-examined within a circle of visiting and re-visiting to allow a deeper understanding with each interpretation and fully understand the 'meaning of being' (Earle 2010). This reciprocal activity of re-examining and re-visiting the data based on the fore-knowledge of the researcher was developed into the concept known

as the hermeneutical circle which has become synonymous with the hermeneutic inquiry (Converse 2012, Dowling 2007). This argument also supports the need for researchers to undertake a literature review prior to conducting the research which is at variance with some supporters of descriptive phenomenology (Finlay 2008, Wojnar & Swanson 2007).

Despite Heidegger's (1962) initial work Annells (1996) believes that it was Gadamer (1900 – 1996) who successfully brought the concept of the hermeneutic circle to the fore of philosophical hermeneutics. Like Heidegger, Gadamer (1976) rejected Husserl's idea of bracketing and added further to the belief that additional understanding could be achieved through bringing pre-existing understandings to the fore, engaging in dialogue and being open to the opinion of others (Annells 1996, Flood 2010, McConnell-Henry *et al.* 2009b). This translates in research terms to the researcher aiming to understand the phenomena articulated based not only on the experiences of the participants but also on the experiences of the researcher. Gadamer termed this reaching of blended understanding between the researcher and the researched as a 'fusion of horizons' (McConnell-Henry *et al.* 2009a). This 'fusion' or 'synthesis' may also lead to participants reaching a new understanding of their experience through the process of description and reflection (Taylor & de Vocht, 2011).

Furthermore the role of previous knowledge was considered to be a fundamental aspect of the decision-making with regard to the philosophical approach adopted for this study.

3.3.4 Descriptive or Interpretive Phenomenology?

When initially embarking on this research a descriptive approach based on Husserl's philosophy was considered to be the most appropriate as although I had clinical experience of looking after children on I-LTV, I did not have experience of looking after my own technology-dependent child and therefore would be able to put aside any beliefs or preconceptions of what it would be like to explore the phenomenon from a parent's perspective. Accordingly with the specific purpose of 'bracketing' my existing

knowledge prior to data collection I went through the process of writing down my beliefs and ideas based on my clinical involvement in the care of these children and their families. However, after reflection and with further consideration and analysis of the literature it became apparent to me that it would be difficult to adopt an approach in which all my previous pre-conceptions, beliefs, motives and biases were suspended from the context of previous experience of looking after children dependent on I-LTV. It also became apparent that many other proponents of phenomenological research felt the same way and this became one of the fundamental reasons why Heidegger rejected the notion of bracketing (Dowling and Cooney 2012). Heidegger (1962) and later Gadamer (1976) claimed that we all have values, experiences and background that we bring with us and that are impossible not to use in the interpretation of experiences. I also recognised that I would have an influence on the research participants themselves, based on their understanding of my knowledge and experience. The parents were all aware that I had existing knowledge of working with children requiring I-LTV and that I knew, to some extent the complexities of the discharge pathway and was aware of some of the problems they were likely to encounter during this process. Furthermore I had met all of the parents previously and had existing established relationships with them having been involved in the care (albeit indirectly) and discharge preparations for their children. I would therefore as described by Gadamer (1976) bring a 'fore-structure' in the shape of values, experiences and background to the research (Koch 1999).

Gadamer (1976) also believed that not only was it impossible to bracket one's beliefs and pre-conceptions but that it was essential to have 'prejudices' to help to understand and interpret findings (Koch 1999). This argument was strengthened further by van Manen (1990) who claimed that 'bracketing', rather than being used to 'shed' all previous knowledge, enhances Heideggerian research and enriches the vigour of interpretative studies (Peters & Halcomb 2015 Heinonen 2015a, Sorsa *et al.* 2015). In support of this notion Matua & Van Der Wal (2015) maintain that in hermeneutic phenomenology rather than pre-understandings being 'bracketed' they

should be integrated and become part of the research findings. According to Heinonen (2015b) this approach to 'bracketing' allows the researcher to develop a new awareness and understanding based on the principle they have been able to identify their preconceptions and assumptions which enables them to become a source of insight which can then be used consciously within the research. This level of 'bracketing' either based on personal values or at a theory based level is very similar to the use of reflexivity, which is recognised as an essential skill for qualitative researchers (Ahern 1999, Haahr *et al.* 2014, Sorsa *et al.* 2015) and is an important component in phenomenological research (Wimpenny and Gass 2000) which is supported in the phenomenological approach of van Manen (1990). Therefore in recognition of the value of bracketing and reduction, I believed further exploration of van Manen's approach to phenomenology was warranted.

3.3.4.1 Max van Manen

Born in 1942, Max van Manen's influence in phenomenology has recently come to the fore due to its ability to offer an alternative approach to phenomenological data analysis which has been widely used in nursing research. Based on the principles of both Husserl and Heidegger, van Manen (2007) suggests combining the characteristics of descriptive and interpretative phenomenology believing that all descriptions contain elements of interpretation (Pringle *et al.* 2011a). Furthermore van Manen did not conform to the belief that researchers can bracket previous experience, recognising their fore-knowledge and role in the experience is essential (Dowling 2007). Rather than rejecting the notion of bracketing as Heidegger did (Peters & Halcomb 2015) van Manen (1990) argued that 'bracketing' and 'reduction' have a role to play in interpretive phenomenology supporting the belief they can be incorporated successfully into interpretive research and strengthen the research by being openly discussed (Heinonen 2015a, Matua 2015, Sorsa *et al.* 2015, Wilson 2015). In agreement, Heinonen (2015a) reasoned that 'bracketing' and 'reduction' are phenomenology's two most critical components allowing the researcher to view the world with an open mind. However, in accordance with Sorsa *et al.* (2015), I recognised

‘bracketing’ and ‘reduction’ have different purposes in descriptive and interpretive phenomenological research. In interpretive phenomenology, fore-knowledge is used intentionally to develop new understanding with researchers repeatedly questioning their existing knowledge in coming to hermeneutic understanding which van Manen & van Manen (2012) believed may lead to phenomenological insights. Furthermore van Manen (1990) claimed that bracketing can be used to identify potential areas of bias and is a means of demonstrating validity with data collection and analysis.

Van Manen (1990) also suggested there was no advocated method for interpretive phenomenology per se and instead directed the researcher to:

1. Turn to a phenomenon that seriously interests them
2. Investigate experience as lived rather than conceptualised
3. Reflect on the essential themes that characterise the phenomenon
4. Describe the phenomenon through the art of writing and re-writing
5. Maintain a strong and orientated relation to the phenomenon
6. Balance the research context by considering parts and the whole

Earle (2010) describes van Manen’s approach to research as an active and ongoing interplay of research activities and suggests the six methodological themes should not be used prescriptively or artificially separated but performed with a practical approach to bring inventiveness and stimulate insight in to the study.

Therefore in accordance with the approach advocated by van Manen (1990) I concluded that my intention to explore the ‘lived experience’ of the participants could be best achieved by using a phenomenological approach based on the philosophical principles of Heidegger whilst using the skills of reflexivity, bracketing and reduction to enhance the validity and rigour of the study (LeVasseur 2003). Acknowledging in all interpretation there will be an element of description (Matua 2015), I was cognisant of the challenges of phenomenological ‘bracketing’ and ‘reduction’ as advocated by Husserl, yet in agreement with van Manen (1990) rather than setting our understanding and fore-knowledge aside we should recognise what has influenced our

view of the world. Finlay (2008) stated that to understand, we must bring pre-existing knowledge to the fore and make known what has influenced the research and individual biases and in doing so we can be open to other people's meanings (Tuohy *et al.* 2013). Lopez & Willig (2004) also considered that the researcher's knowledge should influence the research process and impacts directly on how it proceeds. In accordance with these principles and as recommended by Tuohy *et al.* (2013) it became important to identify my fore-knowledge and pre-understandings so that readers of this research are clear about the study's context and possible influencing factors. Thus using the definitions proposed by Heinonen (2015a) reduction was accomplished in a number of ways including from a heuristic, methodological, eidetic, hermeneutic and concrete perspective and are summarised as follows:

3.3.4.2 Levels of Reduction

- **Heuristic reduction** is used at the beginning of the research, and is concerned with the 'wonder' or having interest in a particular area (Heinonen 2015b). It enables the researcher to ask questions and was used in the context of this study in a bid to seek answers to the question 'what are the experiences of parents whose child has been initiated on I-LTV and is still being cared for within the hospital environment?'
- **Methodological reduction** helps to identify the most suitable methodological approach such as using a phenomenological attitude throughout the research to gather and analyse information from participants (Heinonen 2015c). This was achieved by reviewing the two predominant philosophical research approaches of Husserl's descriptive phenomenology and Heidegger's interpretive phenomenology.
- **Ontological reduction** aims to view the research from the perspective of 'being in the world' (Heidegger 1962) with the purpose of understanding the nature of reality and gain a holistic view of the participants involved. In addition to using van Manen's (1990) research approach the existential themes and modalities of 'spatiality', 'corporeality', 'temporality' and 'relationality' also recognised by

van Manen (1997) were considered throughout the study to ensure a holistic understanding was reached.

- **Hermeneutic reduction** involves the researcher reflecting on any pre-understandings, pre-conceived ideas and known biases and openly acknowledging them (Heinonen 2015c). Hermeneutic phenomenologists should bring with them fore-knowledge and understanding of the experience having already reflected and considered what the experience is like and in doing so integrate them in to the research Matua & Van Der Wal (2015). The belief that rather than the researcher 'tainting' the research data with pre-understanding, it is their known pre-suppositions and reflexivity which facilitates deeper understanding (Flood 2010). Interpretive phenomenology as previously described is a blend of the researcher's understanding combined with the participant's voice regarding the phenomenon which results in a final product which Gadamer describes as the 'fusion of horizons' and Heidegger as the 'hermeneutic circle' (Matua & Van Der Wal 2015).
- **Eidetic reduction** involves listening to, reading and respecting the participant's individual lived experiences and seeing them as unique to them (Heinonen 2015b). This was achieved when conducting the interviews with a conscious effort made not to interrupt the parents' narrations allowing them to speak openly and freely about their unique experiences without interjection whilst showing interest in their descriptions.
- **Concrete reduction** means the researcher should avoid theorising and abstraction *yet allow* for existing knowledge and pre-understanding of the phenomenon under investigation (Heinonen 2015b). In addition to recognising my existing knowledge as suggested by Hamill & Sinclair (2010) I made concerted attempts to put aside any preconceived ideas whilst not denying their existence. Furthermore in accordance with Green *et al.* (2015) I also attempted to use restraint when making judgements about the parents' descriptions.

Although the levels of reduction identified by Heinonen (2015b) have been separated for the purpose of discussion, in practice they formed an overall approach to allow me to achieve a better understanding of the participant's experiences. By being open throughout the research it enabled my fore-knowledge to be reflexively acknowledged which I believe is essential when undertaking phenomenological research. In addition by repeatedly reflecting upon and questioning my existing knowledge in relation to the findings and subsequent meanings interpreted from the parents' descriptions a new hermeneutic understanding would be achieved as described by van Manen (1990).

Finally, Heidegger's hermeneutic phenomenology also recognised the importance of context in relation to the research identifying that individuals are always immersed in a world that impacts on their existence in time and space. Accordingly the social, political, temporal and historical context have a bearing on this study and hence why the background relating to the recent developments in technology and specifically I-LTV have been identified within the literature review to enable enhanced understanding of the contextual relevance for this research study.

3.3.5 Limitations of Interpretive Phenomenology

As with all research there are important limitations to acknowledge associated with the chosen methodology. The purpose of phenomenological research is to explore the way people experience the everyday world in which they live. According to van Manen (1990) interpretive phenomenology does not attempt to predict or generalize and does not aim to solve problems but instead aims at facilitating understanding and interpretation of phenomena and the meanings individuals attribute to their experiences. It differs from other human science research in that it doesn't aim to illuminate meaning specific related to particular cultures such as in ethnography, or from social groups as in sociology. Neither does it aim to elucidate meaning regarding the psychology or biographical nature of the individual's personal life history. In contrast to empirical science phenomenology does not offer explanation of facts and doesn't allow for experimental generalisations as with research related to the natural sciences, yet it is considered as being ideally suited to exploration of the human

experience and has been widely used by the nursing profession (McConnell-Henry *et al.* 2009a).

On a practical note one of the main arguments against phenomenology as described by numerous researchers is there is no one single methodological approach and as stated by van Manen (1990 p.30) “...*there is no method*” and therefore this can lead to difficulty in establishing reliability and validity of the approach adopted. While Mapp (2008) argued phenomenology provides a framework for a method of research, McConnell-Henry *et al.* (2009b) described the approach as a complex methodology which many researchers find difficult to understand. However, the decision was taken to proceed with the approach based on the understanding and the belief the methodology would serve the research area of interest well. As Koch (1999) stated it is important to recognise and state what it is that you want from the research, for example to illuminate a phenomenon, or to sensitise healthcare practitioners to respond in a different or more appropriate way. Therefore in the context of this research the aim was to understand the experience of the parents while remaining open, non-judgemental and compassionate together with acknowledging assumptions, preconceptions and pre-existing judgements already held (Converse 2012, Heinonen 2015c, Matua & Van Der Wal 2015).

In summary interpretive phenomenology based on Heideggerian philosophy and influenced by van Manen’s (1990) approach was chosen as the research methodology as it focuses on the ‘lived experiences’ of the individuals or participants which held true to the intention to explore the ‘life-world’ of the parents involved in caring for their technology-dependent child in hospital. Additionally fundamental to Heideggerian philosophy is the belief that the researcher should not only bring their preconceptions, knowledge and understanding to the research but also that these should be interwoven in to the research as a shared understanding or a ‘fusion of horizons’ as identified by Gadamer (Dowling 2007, McConnell-Henry *et al.* 2009b). This ‘fusion’ and encouragement to include my preconceptions led me to believe that I had made the right decision to choose this methodology as it felt directly applicable to my

role as a practitioner and as a researcher in studying towards a professional doctorate (DHSci) with the research having direct relevance to my practice.

The next section of this chapter describes the research method used to conduct the study with reference to dynamic interplay of the six research activities described by van Manen (1990) and the influence of Gadamer's philosophical hermeneutic principles (1976).

3.4 Research Method

Phenomenology is the study of the 'lived experience' and aims at gaining a deeper understanding of the nature or meaning of our everyday lifeworld (van Manen, 1990). To achieve such a goal the research methods chosen for data collection and analysis were based on the methodology of interpretive phenomenology as this approach aims to gain understanding and involved elucidating data from the 'lived world' of the participants. A description of the process and techniques used now follows and begins by describing the research and clinical governance adopted followed by explanation of the approach to gaining study approval, participant sample and recruitment and ethical considerations. This section will also provide detail on the data collection and analysis technique used and will conclude with a review of the study's rigor and trustworthiness.

3.4.1 Research and Clinical Governance

As stated in the Research Governance Framework for Health and Social Care (Department of Health 2005b), everyone involved in the conduct of clinical research must have training to ensure they are best prepared to carry out their duties. A key requirement for anyone involved in the conduct of clinical research is Good Clinical Practice (GCP) training which the National Institute for Health Research (NIHR) states is the ethical and practical standard to which all clinical research should be conducted (NIHR 2016). In accordance with this the researcher had completed GCP training in August 2013. In addition as the study would also indirectly involve NHS patients, NHS Trust Consent Training was also successfully completed in February 2014 prior to

starting the study. Additionally the researcher's clinical conduct was guided by the Nursing & Midwifery Council Code of Professional Conduct (NMC 2008) which presents the professional standards that nurses and midwives must uphold at all times.

3.4.2 Study Approval

Ethical approval for the study was sought and gained from the Faculty Research Ethics Committee at De Montfort University in December 2013 and the NHS Research Ethics Committee (NHS REC) via the online Integrated Research Approval System (IRAS) in March 2014. In addition to gaining ethical approval as the participants were parents of children who were current or previous patients at a local hospital trust local Research & Development (R & D) approval was sought and gained via the trusts R & D department. Once both NHS ethical and NHS Research & Development approval had been obtained participants were invited to take part in the study and recruitment began in April 2014.

(Copies of the ethics and R & D approval obtained are included in Appendices 7.1 – 7.4)

3.4.3 Participant Sample

Participants for the study were selected using purposive sampling. Purposive sampling as articulated by Creswell (2008) permits the selection of identified participants who have first-hand experience and knowledge of the phenomena being explored and in addition are able to articulate the meaning of their experience. In the context of this study the participants were the parents from a purposive sample created from a known cohort of children that had been commenced on I-LTV during the previous three years. The children were known by the researcher from her clinical role as the Long-Term Ventilation (LTV) Coordinator for Specialised Commissioning and since 2010 a database of all children who had been initiated on I-LTV within the region had been compiled for clinical recording purposes. The majority of children had been discharged from the hospital setting within the previous year, with five of the eight children having been discharged within the preceding 3 to 6 months from the time of the interview. The study also included parents of children that were medically stable but

still in the process of being discharged with two of the children still in hospital at the time of the interview and only one child had been at home for greater than a year. As Mapp (2008) identified phenomenology samples can represent those who are 'living' the experience or who have lived it in the past. It was acknowledged that the length of time since discharge may potentially affect memory recall although hopefully this would allow the most vivid of their experiences to be recollected. Therefore by including participants at varying stages of the discharge process it would bring different perceptions and raise important issues unique to the individuals.

3.4.4 Participant Recruitment

Following NHS R & D and ethical approval, a letter of invitation and Participant Information Sheet (PIS) providing information on the study was sent via the post to all parents of the children identified in the cohort (n = 32) inviting the parents to participate in the study. The participants were invited to contact the researcher either by telephone or email to discuss the study in more detail or indicate their willingness to be involved. Sixteen parents from eight families expressed an interest to take part in the study and contacted the researcher by telephone or email. Following agreement to participate in the study the researcher arranged to meet with the parents at a mutually agreed time at a place of their choice. (Copies of the study letter of invitation and PIS can be found in Appendices 7.7 & 7.8)

All parents responding positively to take part in the study were included and invited to be interviewed with interviews taking place between April and October 2014 with all participants choosing for the interviews to be conducted within the family home. Location of the interviews as acknowledged by Grbich (1999) is of particular importance and selection of the home allows the participant to feel more in control and at ease leading to a sense of equality minimising the difference in status and power which may have previously been apparent in the clinical context between the researcher and parent. In accordance with the researchers awareness and recognition of the safety aspects of staff working alone outside of the hospital building, the hospitals trust's Lone Worker Policy was read with particular reference to the Good

Practice Points and checklist for Domiciliary or Home visits. However, the researcher was already familiar with the content as she was involved in home visits in her clinical role. The venue and exact location of the interviews were recorded as home visits in the electronic work diary and a mobile phone was taken to all interviews.

In phenomenology the researcher should use a small group of participants to gain rich and in-depth insight in to their experiences (Koch 1999). However, Pringle *et al.* (2011b) argue if the group is too small it may limit the insights gained from a broader perspective and there would be comparatively little to gain from the study in as much as it would only relate to that particular group of participants. Although the focus was to explore the experiences of a particular group of parents with the unique characteristics of caring for a child requiring I-LTV the intention was generate understanding that could be applied to the wider context and serve to improve future experiences of parents in similar circumstances.

All of the 16 parents agreeing to take part in the study responded as couples, either married or unmarried and had been together in their relationship for some time although no further details regarding their relationship were requested as it was not felt to be relevant to the focus of this study. The parents ranged in age, ethnicity, socio-economic status and education and all were over the age of 18 years at the time of the interview. Although the demographic data of the participants was known by the researcher further details have not been provided here as the sample size was so small and potential the identity of the respondents could be more easily recognised if further details were disclosed. Furthermore in accordance with Norlyk & Harder (2010) participant demographics are not of major interest or concern in research using a phenomenology methodology as the intention is to reveal experiences that are unique to the individual whilst not focussing on details such as gender, age or socio-economic class.

At the time of the interview two of the eight children who had been commenced on I-LTV remained in hospital waiting to be discharged home. Out of the eight children

concerned six of them were less than four months old when the I-LTV was commenced and at the time of the interview five of the eight children were still under a year old. Out of the three remaining older children, two were pre-school age and one was a teenager. For three families the child on I-LTV was their first child whereas five families had older children. No siblings were offered the opportunity to be interviewed or took part in the study although the involvement of siblings was considered by the researcher when first planning the study. However, although the experiences of the siblings would be highly relevant, after consideration and discussion with supervisors the decision was taken not to interview the siblings as the focus was to explore the experiences of the parents rather than the wider experience of the family.

3.4.5 Confidentiality & Anonymity

Researchers have an obligation to protect the confidentiality of the research participants (Beauchamp & Childress 2001, Denscombe 2008) and therefore the issues of anonymity and confidentiality were discussed with all the parents prior to them providing written consent to participate in the study. Accordingly it was agreed the use of pseudonyms and camouflaging details would be used to minimise the potential for readers to identify the parents with a unique number given to the parents that was only known to the researcher.

Participants were also given the opportunity to discuss the nature and purpose of the study prior to consenting to take part in the research and informed their participation in the study was entirely voluntary. All were left for a minimum of 24 hours from indicating their willingness to participate before they were interviewed as identified as good practice in the GCP and NHS Consent training attended in February 2014. Parents were also assured that the care they or their child received would not be affected should they choose not to participate or withdraw from the study at any point. In accordance with research requirements written consent was obtained from all 16 parents individually prior to the interviews taking place. The participant consent form included sections on the agreement for the interview to be audio recorded and for non-identifiable quotes obtained to be used in the research report and any

publications arising from the study. (A copy of consent form can be found in Appendix 7.9)

3.4.6 Ethical Considerations

Careful consideration regarding consent was taken with all the parents and all were treated with sensitivity and respect. As most of the parents were at home at this time they were not directly in contact with the researcher, however two children were still in-patients at the time of interviews. Therefore care was taken not to visit the ward or contact the parents during this time of consideration in case it put pressure on the parents to participate. It is well recognised that parents are in a particularly vulnerable position when in hospital (Hallstrom *et al.* 2002) and may feel obliged to participate by either wanting to please the researcher or assessing that if they declined to participate this may affect the care of their child.

As Duffy (2012) highlighted researchers should be aware that the recollection of events can be an intensely emotional experience and has the potential for profound personal change. Accordingly it was acknowledged by the researcher that during the interview some parents may find the experience of discussing the time spent in hospital with their child distressing and therefore this issue was specifically addressed during the recruitment process and via the patient information sheet and verbally by the researcher prior to the interview commencing. All participants were advised that if they became distressed during the interview they could either stop for a break or terminate the interview early. In addition the participants were advised the researcher would also use her own judgement to terminate the interview if at any time she felt the parent was becoming too distressed. Following exploration of what support was available for parents should they become distressed the decision was taken that in the event of this happening the parent would be supported and comforted by the researcher at the time and advised to contact their GP for advice or referral for further support and counselling or contact the local Patient Advisory Liaison (PALS) service with the contact details provided on the Participant Information Sheet (see Appendix 7.8).

During the interviews a number of parents did become emotional when recalling their experiences and with this occurrence the interviews were paused giving the parent time to recover and regain composure. All were asked whether they wished to continue with the interview and in one situation the researcher took the decision to terminate the interview early due to the mother becoming very tearful. At the time the mother was immediately comforted and given support by the researcher and her partner and she recovered sufficiently to state she would be happy to continue with the interview. However, the researcher also offered the opportunity for another date for the interview to take place, which was accepted.

3.4.7 Data Collection

Phenomenological research permits a wide range of data collection methods such as interviews, informal conversations, diaries and art-work yet all seek to gain narratives of the 'lived experience' as experienced by the first-person (Wilson 2015). Yet as Mapp (2008) describes, unstructured interviews are often considered to be the optimum method for data collection in phenomenological research. In hermeneutic phenomenology van Manen (1990 p.66) suggests the interview serves two very specific purposes:

- 1) *It may be used as a means for exploring and gathering experiential; narrative material that may serve as a resource of developing a richer and deeper understanding of a human phenomenon*
- 2) *The interview may be used as a vehicle to develop a conversational relation with a partner (interviewee) about the meaning of an experience.*

In keeping with the hermeneutic approach the decision taken for this study was to conduct face-to-face interviews with parents scheduled at a time suitable for them and in a location where they felt comfortable, at ease and more in control. According to Denscombe (2008) it is important to enable the participants to feel at ease as the quality of the data depends to some extent on the relationship between the researcher and the participant and in phenomenology the researcher should get "*as close as possible to the essence of the others*" life experiences (Grbich 1999 p.92).

Through my clinical role I had previously met all the families and established positive professional relationships with them which I believed would be beneficial to gaining in-depth information. Although when conducting a phenomenological study the relationship between the researcher and participants is recognised as important (Lester 1999) the conflict between my clinical and research roles was recognised as a potential area of ethical concern by the National Research Ethics Service (NRES) committee. However, at the time of application I was able to confirm that from April 2014 and prior to the commencing the interviews I would be starting a 12 month secondment away from the hospital and therefore she would not be involved in the care of the children. This was accepted by the NRES committee and approval was given as a full explanation of the change in circumstances had been provided.

The letter of invitation and PIS sent to the parents prior to the interview advised the research was being undertaken as part of academic study (DHSci) and again this was discussed with the parents at the time of the interview. The role of a research student was also explained as being completely separate to my clinical role although the areas of interest and research subject were clearly linked. I also informed the participants that I would be on secondment at the time of the interviews and not involved in the care of their children. This was acknowledged by all the participants and I again verbally reinforced that participation in the study would not affect the care they or their child would receive at home or in the hospital.

All interviews were conducted face-to-face with both parents being present throughout the entire time. Verbal agreement and written consent for the interviews to be audio digitally recorded was obtained prior to the interviews commencing and an approximate time limit of up to 90 minutes was agreed for each of the interviews. An unstructured interview technique, appropriate with hermeneutic phenomenology (van Manen 1990) was considered the most suitable approach to explore the parents experiences of the time spent in hospital. Because the main goal of unstructured interviewing is to understand areas of importance to the researched Fontana & Frey (1994) believe it is paramount for the researcher to establish rapport with the

participants. Therefore prior to the interview commencing general conversation was established with the parents and although this was recognised as good practice in terms of using an unstructured approach it was natural to enquire about the well-being of the child and family as a pre-existing relationship was already established.

The interview commenced with a general introductory open-ended question asking the parents to tell of their experiences in their own time. Allowing the interviews to be unstructured enabled participants to bring experiences that were important to them without the researcher leading them to areas considered to be of importance (Crotty 1996). As identified by Holloway & Freshwater (2007) appreciation and understanding are attained through listening to people's stories and one of the most useful qualitative interview techniques as described by Munhall (2012) is to start the interview with one open ended question such as 'Tell me what it was like for you?' Using broad open-ended questions to enquire about the phenomenon of interest leads to textural and structural description of the experience from which an understanding of the common experiences can be gathered (Creswell 2007). Further probing questions were used during the course of the interview to explore areas of interest further. Questions such as 'Can you tell me how you felt at that time?' were used whereas at other times the probes were less direct and sounds and gestures of empathy or acknowledgement were used to encourage the parents to expand more. Denscombe (2008) identified the importance of the researcher being sensitive to the feelings and emotions of the participants as not only does it encourage more detailed description but also acknowledges the researcher's sensitivity to the stories being told.

Although verbally a suggested time limit of up to 90 minutes had been discussed prior to commencing the interviews I was cognisant that I would allow the interview to continue should the parents wish to describe further details of their experiences. Visual non-verbal gestures and interactions occurring during the interview were mentally noted but not recorded in writing during the process as I wanted to remain actively engaged in the listening process. Also being observant to the body language and non-verbal signs given by the participants gave information as to the when the

interviews were naturally coming to a closure. Each interview concluded with asking the parents if there were any further issues or information that had not been mentioned that they felt as parents they would like to discuss or future parents to know. Examples of the interview schedule and additional questions can be found in Appendix 7.10. In addition reflective notes were made as soon as possible following the interviews to support the data and as Denscombe (2008) defined it can help to fill in some of the non-verbal communication and aids recollection on what people do rather than just say.

Consideration of alternative approaches to data collection was given during the design phase of the study with the use of semi-structured interviews deemed as a potential alternative although not strongly favoured as an approach in phenomenology (Koch 1996). Some phenomenological researchers have used semi-structured interview techniques, reasoning that this allows the researcher to keep the phenomena of interest as the focus (Wimpenny & Gass 2000). Therefore using semi-structured interviews to elicit data would allow the researcher to develop a series of questions that were considered to be of importance to the research but may restrict the participants leading the discussion to areas they regarded as significant (Grbich 1999, Polit *et al.* 2001, Silverman 2010). Additionally the areas addressed may not be of importance to the participants and therefore using an unstructured approach would allow the parents to raise issues that were important to them. Furthermore detailed, reflective, open and honest accounts of the parents' time spent in hospital may be less forthcoming and more difficult to access if a rigid set of questions or a more structured interviewing technique were used (Pringle *et al.* 2011b). Therefore the use of unstructured approach was employed as the aim was to explore the lived experiences of the parents.

3.4.8 Pilot Interview

A decision was taken to pilot the unstructured interview with two parental couples with any amendments to the interview schedule and revision of questions made prior to interviewing the rest of the participants. Following the first interview an

anonymised transcript of the interview was sent to my research supervisors for checking and validation of content (Silverman, 2010). After review and discussion it was decided there was no requirement to amend the interview schedule therefore it was agreed to continue with the study without any further changes being made.

3.4.9 Main Data Collection

A total of eight interviews (16 participants) were conducted over a period of six months with detailed contribution from both the mothers and fathers with seven of the interviews lasting between one and two hours. One interview was terminated early after approximately twenty minutes due to the mother becoming emotionally upset. Whilst other parents, notably mothers, also showed signs of emotion during the interviews most parents appeared to enjoy speaking about their experiences and spoke openly and freely producing rich and detailed information with interviews yielding between 3,500 – 21,000 words, totalling almost 100,000 words.

3.4.10 Joint Interviews

As previously indicated all interviews took place with both parents being present. According to Taylor & de Vocht (2011) Heidegger's philosophy does not suggest a preference for conducting joint or separate interviews but consideration should be given regarding the benefits or disadvantages of using one approach over the other.

Unlike the positivist view of the world, phenomenology rejects the notion that there is one reality and instead accepts that experiences can be seen in different ways by different people at different time and that each experience is valid in its own right bringing multiple realities (Denscombe 2008). Interpretive phenomenologists recognise it is important for the experiences to be considered in the context of the situation (van Manen 1990, Racher 2003, Taylor and de Vocht, 2011). The term '*Dasein*' taken from the German verb 'to exist or to be there' is the principle belief of Heideggerian phenomenology and that you cannot exist as an individual in isolation but can only exist within a world in which other beings and entities continually engage (Wilson 2015). Thus the stories the parents told jointly were a way of them making sense of

the experience they had shared in the context of them as a couple and as the parents of their child. In this situation the data was co-created and therefore well suited to the research aim to explore the experiences of the parents (Racher 2003) and supports the argument to offer joint interviews supporting Heidegger's (1962) notion for participants to jointly describe their experiences and shared understandings of the situation. However, as the presence of the other significant person or persons is not dependent on the actual physical presence it would also have been reasonable and in keeping with the phenomenological approach to have interviewed the parents separately, yet without exception all the parents involved in the study chose to be interviewed together which provided consistency across the study.

In the context of joint interviews there is the potential for three different perspectives of the participants, those of the parents individually and also of them as a couple. It was recognised the way a mother and father interpret and makes sense of the experience may differ and the presence of another may alter the recollections and stories told (Morris 2001). Added to this there is the perspective of the researcher therefore multiple perspectives are possible (Taylor and de Vocht, 2011). However, it is also recognised that the presence of the partner or other may also affect revelations with some individuals not choosing to share information for fear of criticism, conflict or encountering difficulties (Morris 2001). Conversely partners may also facilitate disclosure or un-concealment in Heideggerian terms, when they are able to prompt the other or add additional information which adds to the shared reconstruction of the experience (Taylor and de Vocht, 2011) and contributes to the production of rich data (Bjørnholt & Farstad 2014, Morris 2001). Additionally having both parents present may allow couples to corroborate or modify their stories and therefore may present a more realistic or truthful picture which helps to increase authenticity (Taylor and de Vocht, 2011).

From the perspective of this particular study there were clear benefits for parents co-constructing their stories as recognised by Koch (1995). However, it is also acknowledged it would have been advantageous to have had the benefit of conducting

separate interviews and in doing so bring an additional perspective of individual meanings as well as shared meanings to the study. Nevertheless it could be argued in this context the research aimed to capture the experience of parents and by definition unless there were any single parent families interviewed, then the traditional concept of having a mother and father with joint responsibility for the care of their child provided the opportunity to learn from the collective shared experiences and meanings attributed to them. As Racher (2003) argued, when seeking to understand the experiences of parents then it is entirely appropriate for the research method to focus on the parents as a unit of the study.

In summary, the concept of interviewing parents separately or together was considered based on the understanding that each approach would be likely to bring different outcomes (Taylor and de Vocht, 2011). Combining the perspectives of both the individual and the couple's perspectives would have undoubtedly added further to the richness of the data and as a result would have supplemented the findings however this was not possible due to the preferences of the participants.

3.4.11 Data Analysis

As with all data analysis the purpose is to organise, provide structure, bring clarity and elicit meaning from the gathered data (Polit *et al.* 2001). Yet phenomenology also resolves to *"preserve the uniqueness of each lived experience of the phenomenon, while permitting an understanding of the meaning of the phenomenon itself"* (Banonis 1989 p.38). The phenomenology approach is deemed to be well suited to broadening people's understandings especially as it is able to produce rich and meaningful descriptions of experiences to help people get a 'real' impression of what has been experienced. Matua & Van Der Wal (2015) believes that it is the description of the 'as near to reality' impression that is critical to enable others to understand what the participants have experienced. In the context of nursing, phenomenology is therefore a useful approach to use to help nurses improve their care and understanding based on the experiences of patients and in this context parents and how the individual experiences have been interpreted. However, unlike descriptive phenomenology the

aim of interpretive (hermeneutic) phenomenology is to describe, understand and interpret participants' experiences (Tuohy *et al.* 2012).

Hermeneutic interpretation seeks to understand meanings that are expressed openly in the data along with meanings and understandings that are un-expressed but come to light with the interpretations of the interpreter. Researchers using the interpretative approach to data analysis acknowledge that there are multiple levels of understanding which leads to understanding the whole and the parts of the text which fit with the notion of the hermeneutic circle. Multiple intersubjective meanings can be drawn from the interviews which can bring added richness to the data. There is no one truth but many truths hidden within the text (Charalambous *et al.* 2008).

It is recognised that phenomenology has no set structure or process to assist with data analysis and there are a number of methods available to support this essential part of the research (Dowling 2007). A range of frameworks have been formulated by psychologists to help researchers structure the analysis of the data and researchers are encouraged to exercise their judgement to use the data analysis principles flexibly to meet their needs (Flood, 2010). Despite the variety of methods it is important to select one that remains true to the philosophical approach chosen for the study (Converse 2012, Matua 2015, Polit *et al.* 2001). Having reviewed a range of different approaches the decision was taken to use a modified approach of analysis based on a combination of the six research activities identified by van Manen (1990) and the hermeneutic principles of Gadamer (1976). As there is no one preferred or recommended analytic structure, Koch (1999) accepted researchers may develop their own framework to analyse data of the phenomenological inquiry. Multiple methods may be used however as Matua (2015) argues the method of analysis needs to be clear, systematic and reproducible. An overview of the steps taken in the data analysis process is presented in Table 2, however further information is given below to provide clarity on the approach used.

Table 2: Overview of the Method of Analysis.

	Method of Analysis
Step 1	Initial familiarisation Interviews transcribed and resulting transcripts read through several times, with notes and reflexive comments made.
Step 2	Initial identification of codes & key words Identification and highlighting of key words, phrases and metaphors within the transcripts and on the computerised texts
Step 3	Reflection on initial codes & key words Review of audio tapes and interview transcripts, relating back and linking initial codes to quotes in text, using a iterative process
Step 4	Identify connections and emerging themes Identification of potential links and emerging themes identified in each transcript
Step 5	Repetition of process Repetition of process with subsequent interview transcripts with cross-analysis of the data which revealed clusters of themes
Step 6	Connection of themes using mind-maps Connection of cluster themes from the texts into main themes, with related sub-themes identifying contextual significance
Step 7	Returning to the data Re-examination of transcripts for greater depth of meaning and interpretation in consideration of part and the whole.
Step 8	Summary of main themes Production of a summary table of main themes, considering the parts and the whole of the transcripts
Step 9	Production of interpretive account Production of a detailed, interpretative, reflexive written account based on the main themes and sub-themes derived from the data
Step 10	Identification of over-arching concepts Overarching concepts identified from the main findings of the study with appropriation of new knowledge and insight

3.4.11.1 Transcription

All the interviews were saved on to a digital recording device in preparation for transcription but the actual process of transcribing the data was delayed until after all the interviews had taken place apart from after the first pilot interview. This approach was taken as during the interview phase I wanted to allow each individual interview to bring its own unique data rather than being led by what had previously been heard.

Although it was recognised that I would have an overall sense of what had been described during each interview I felt it was important to not transcribe and begin analysis prior to completion of the data collection.

As Silverman (2010) identified transcription of interview data is an important part of qualitative research and can take a considerable amount of time, yet in an attempt to become thoroughly familiar and immersed in the data (Polit *et al.* 2001) the decision was taken to transcribe all eight of the interviews independently. Although in reality this took many hours the decision not to have any assistance with transcription proved invaluable as I became increasingly conversant with the data which undoubtedly helped with the analysis. As Denscombe (2008) advised, only by becoming thoroughly familiar with the data is the researcher in a position to begin to code the information. Once all the data collection had been completed the interviews were listened to and transcribed initially on to Microsoft Word. Following this the transcribed text was entered onto a computer software package (QSR Nvivo10) in preparation for analysis of content and identification of key themes (Silverman, 2010) using the 'selective or highlighting' approach identified by van Manen (1990).

3.4.11.2 Thematic Analysis

Following initial familiarisation and transcription of the data (Step 1) the next step was to highlight key words or phrases and assign descriptive codes to the data in the first step of identifying themes (Step 2). Key words, phrases and metaphors were highlighted in a process of free, emergent and unorganised coding in accordance with van Manen's (1990) 'Selective or highlighting' approach. Van Manen (1990 p.92) suggested three possible approaches to identifying themes or aspects of phenomena in hermeneutic phenomenology these being:

- i) Wholistic¹ or sententious approach
- ii) Selective or highlighting approach
- iii) Detailed or line-by-line approach

¹Spelling of 'Wholistic' taken from van Manen (1990 p.92)

However, due to the volume and extensive nature of the findings it was considered unmanageable to adopt a detailed line-by-line approach in light of the limited time and resources in undertaking the study. Additionally using the 'Wholistic' approach in isolation was judged to be less suited to the research aims as it was anticipated that this may miss themes that were more striking or unusual and therefore I concluded that a more detailed exploration of the findings was warranted.

Using the selective approach, key words and phrases felt to be particularly revealing unusual or essential were highlighted on the texts and also electronically using the software package (QSR Nvivo10). Using the computer programme enabled ease of returning to the transcripts to see the code or key phrase in the context of the interview and corresponding text. It also helped to facilitate management of the data and allowed retrieval of quotes from the interview transcripts (Denscombe 2008). By the end of step 2 a total of 237 codes had been formed from data from the eight interviews. Having completed the initial identification I realised that by the end of this stage there were significantly more codes than at the beginning and therefore the transcripts were listened to again using an iterative approach to reflect on the initial codes and ensure that data was assigned to the additional descriptive themes (Step 3). It was at this stage that a number of the original codes were found to be redundant or used minimally and that some of the data codes were revised. This stage was in keeping with Bryman's acknowledgement that coding in qualitative data analysis tends to be "*in a constant state of potential revision and fluidity*" (Bryman 2001 pg. 392).

During steps 2 and 3 there was no intent to make any interpretations or sense of the data however, during steps 4 to 6, emerging themes were identified and transcripts were checked for potential links and commonalities. It was at this stage mind-maps of all eight interviews were developed clustering the salient themes and beginning to identify potential main and related sub-themes. Appendix 7.11 provides an example of the mapping analysis of one of the interviews. During this stage the computer software package was also used to identify key words but the preference to work with the mind-maps to visually work with the data meant the computer software (QSR Nvivo 10)

became of less value. By the end of step 6 a descriptive account of the 'lived experience' of the parents could be articulated which was recognised as van Manen (1990) as being essential to the interpretive process as he emphasised a study of the world before reflection was required in the interpretive process (Dowling 2007) .

Familiarity with the data grew with the iterative process of reading and repeatedly returning to the interview transcripts as the codes and key words and phrases were redefined which resulted in further immersion in the data (Step 7). With further analysis and reflexivity an in-depth understanding of the data began to develop with recognition this was in keeping with Gadamer's (1976) hermeneutic circle in which the researcher moves between the whole and the parts of the text and then back to the whole again. (An example of the emerging thematic analysis is presented in Appendix 7.12)

In step 8 a summary table of the main themes and sub-themes developed from the whole and parts of the texts was produced with four main themes identified (see Appendix 7.13). Based on the findings and themes developed an interpretive account was written using illustrative quotes from the parents to highlight the main themes (step 9). Benner (1994) argued researchers should avoid projecting one's own world on to that of the participants and should stay open and true to the text, being prepared for text to disclose concepts that were unspoken and thereby reveal hidden meaning. In keeping with Benner (1994) my intention was for the research findings to be illustrated with direct quotes from the parents to support the notion of remaining true to their experiences. This detailed account can be found in chapter 4 which immediately follows this chapter.

Finally from deeper understanding achieved through the process of describing and interpreting the parents' findings, new knowledge and insight was gained in to their experiences of their time in hospital caring for their technology-dependent child. The final product enables deeper understanding through use of the hermeneutic circle and is described by Gadamer (1976) as a 'Fusion of Horizons'. Together with this enhanced

understanding of the phenomenon of interest what appear to be two over-arching concepts were identified relating directly to the parents 'lived experiences' and completed the analysis stage of the research (step 10). With finalising this step the goal of the research study was achieved as identified by (Matua and Van Der Wal 2015) who stated the goal of hermeneutic phenomenology is to identify meaning from the blend of the participants' and the researchers understanding of the phenomenon being studied.

Prior to presenting the descriptive and interpretive account of the research findings this chapter on research methodology will conclude by reviewing the study's validity, trustworthiness and rigour.

3.4.12 Validity, Trustworthiness and Rigour

Qualitative researchers have long been concerned with finding ways to demonstrate their research findings reflect a true representation of the phenomena being studied (Grbich 1999) with Denscombe (2008) identifying a lack of scientific rigour as one of the main disadvantages of phenomenology. Researchers have attempted to address this with many authors suggesting ways to demonstrate validity, trustworthiness and rigour with Creswell (2007) stating the importance of researchers indicating the study's rigour and phenomenological validity and Koch (1996) referring to rigour as the study's reliability and validity. As Silverman (2010) identified 'validity' is another word for truth and as defined by Grbich (1999) validity lies in readers of the study being persuaded that the researcher has truthfully represented the world of the participants being studied. To begin to establish validity and rigour a review of the study's trustworthiness is examined.

Polit *et al.* (2001) recognise that many researchers use the criteria outlined by Lincoln & Guba (1985) to establish the trustworthiness of their study, these being credibility, dependability, confirmability and transferability. Yet as Norlyk & Harder (2010) contend these criteria are generic for qualitative research and are not specific for a phenomenological study. They suggest the researcher should include as a minimum

articulation of methodological keywords, identification of the investigated phenomenon, and description of how an open attitude was adopted throughout the research process. Therefore in an endeavour to cover these criteria within the thesis I have attempted to provide this information with inclusion of a description of the methodological keywords 'intentionality', 'bracketing or epoché' and 'reduction' in section 3.3.2. Identification of the investigated phenomenon is detailed in the introduction to the study in chapter 1 and literature review in chapter 2. Furthermore through discussion on the use of bracketing and reduction I have attempted to demonstrate how an open approach to the research was adopted. Additionally, in accordance with Matua (2015) in an effort to make this research phenomenologically acceptable detail has been provided on the methodological considerations of the study with the research focus and design, data collection and analysis included within this chapter. Koch (1996) also advocated that in hermeneutic phenomenology the decision trail regarding philosophical and methodological choices should be made explicit for others to follow should they wish as this becomes an important indicator of trustworthiness. This has been achieved through articulating the research steps taken based on an approach established by van Manen (1990), with an example of the audit trail detailing how the main themes were identified presented within Appendix 7.12. To further enhance the trustworthiness I took the decision to personally transcribe all the interviews verbatim and although in practical terms this took many hours, the benefits were that I became thoroughly familiar with the data. Subsequent immersion in the data occurred over the many months that I reviewed and revisited the findings.

In presenting the findings careful and detailed attention was paid to the use of illustrative verbatim quotes which were used to facilitate understanding and elucidate the findings (Wertz *et al.* 2011), supporting the areas being discussed and helping to bring context and transparency to the themes. Matua & Van Der Wal (2015) recommend that the descriptions and individual accounts of events should be presented in such a way that anyone reading them should be able to understand both the facts and the emotions felt during the experience. This in itself helps the vividness

of the descriptions enabling the reader to become more aware of the phenomenon directly experienced and '*opens a window*' onto the lifeworld of the participants (Matua & Van Der Wal 2015 p.33). It was not my intention to uncover or discover factual truths about the experiences of the parents' time spent in hospital with their technology-dependent child. The perspective taken was the interviews were actively constructed narratives of the parents' perspectives of their individual experiences and not true or false reports of the parents' experiences.

Considerable time was also spent reflecting on whether the transcripts should be returned to the parents and there appear to be contrasting views on this as 'member-checking' has long been considered as one of the techniques to improve rigour in qualitative studies (Grbich 1999). Yet Caelli (2001) suggests the practice of returning transcripts to participants to review, clarify, or validate tentative findings depends entirely on one's theoretical stance. McConnell-Henry *et al.* (2011) and Webb (2003) suggest that member-checking is incompatible with phenomenology as there is no edict in interpretive research to prove or generalise findings. This is based on the principle of the participants account being true at that particular time and on reflection may change their recollections and alter their initial beliefs and perceptions. Therefore in accordance with this principle the transcripts of the interviews were not returned to the parents for checking. However, the findings were discussed with my supervisors and colleagues involved in caring for children on I-LTV as it is also recognised that 'experts' can help to corroborate the findings (Whitehead 2004), facilitating further insight and depth through challenge and discussion (McConnell-Henry *et al.* 2011). Nevertheless this principle was employed knowing that multiple truths exist and interpretation in hermeneutic phenomenology can change dependent on the context and experience of those involved in interpretation.

In hermeneutic research recognising the influence the researcher has on the study and the researcher's own experience is integral to the study. Whitehead (2004) contends that it relies on the self-awareness of the researcher to record their understandings and fore-knowledge. Therefore in recognition of the influence my clinical background

and experience in caring for children on I-LTV would bring to the study I set out my previous roles and context within the introduction for readers to be aware of and add transparency to the study. Moreover in accordance with Laverty's (2003) belief of bracketing being central to the rigor of the study details of the different levels of reduction have been included within section 3.3.4.2.

In phenomenology as with some other analysis approaches the interpretation is that of the individual analyser and therefore is subject to bias and criticism in so much as to whether another analyser of the research would come to the same interpretations and conclusions. This as discussed earlier can give rise to doubts regarding the significance of the findings (Pringle *et al.* 2011b). However, in accordance with Smith *et al.* (2009), I consider that the findings from this study are a true and credible reflection of the participants' accounts nevertheless they will not be the only credible accounts that are possible given another researcher's analysis. On reflection, what would have been helpful and could be considered for future studies is to use additional methods of research to support the findings such as the use of parent diaries or participant observations. These methods could then be utilised as part of the analysis and would assist with method triangulation and build upon the validity and rigour of the study. As this was not built in to this research design I accepted that I would have to discuss the analysis and findings with my supervisory team and professional colleagues who were also involved in caring for these children and parents.

3.4.13 Summary

De Witt & Ploeg (2006) argue that due to the methodological inconsistencies and prominence of philosophy in interpretive phenomenology using a generic set of qualitative criteria is challenging and creates difficulty in fully expressing validity and rigour. Yet as Tan *et al.* (2009) asserted unless there is clear process and accountability of the methods used to interpret the text then the process can be open to criticism and scrutiny. While validity and rigour continue to be the subject of controversy in the literature a review of the study's trustworthiness has been achieved by clearly

describing the research process taken based on the tenets of hermeneutic phenomenology.

This chapter has discussed the philosophical underpinnings of this research study based on Heidegger's interpretive phenomenology and has provided detail on the research process undertaken. The following chapter presents the research findings based around the main themes identified from the parent's interviews. The sub-chapters are titled using direct quotes taken from the parents' descriptions and aim to capture the essence of their time in hospital caring for their ventilator-dependent child. The four chapters are titled 'Going into the Unknown', 'This wasn't what we wanted', 'Safer at Home' and 'Clawing every little bit back' and taken together culminate in what appear to be the overarching concepts of 'uncertainty' and 'transitions'.

4 Study Findings ‘Transitions of Uncertainty’

This chapter presents an overview of the study findings and in keeping with van Manen’s (1990) approach to interpretative phenomenology begins to accomplish the elements of describing and interpreting the parents lived experiences of the time they spent in hospital with their technology-dependent child. Further in-depth review and discussion of the findings in relation to the related theoretical concepts and literature examined post-analysis is presented within the Discussions chapter (Chapter 5).

4.1 Main Themes

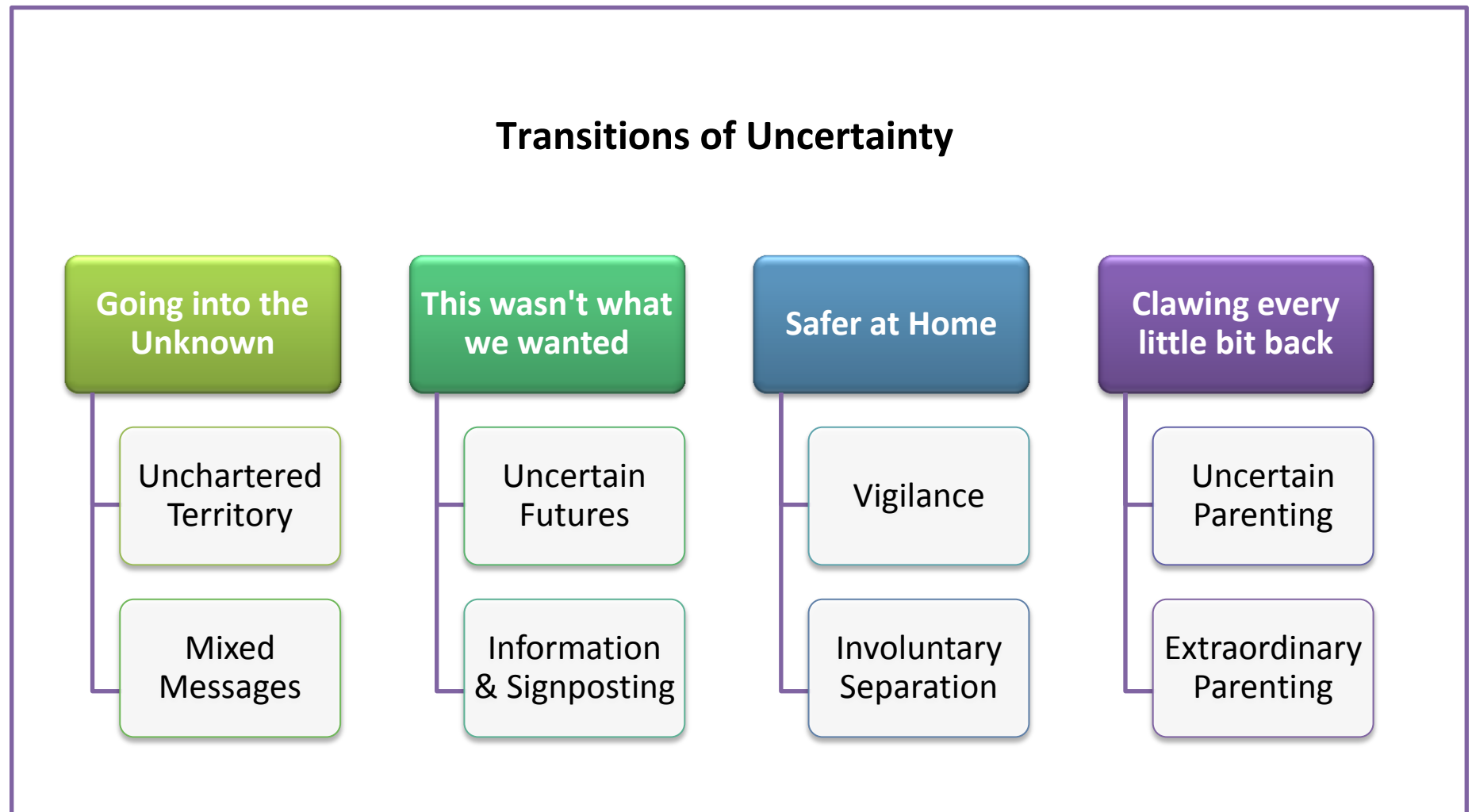
The data derived from the parental interviews was rich and insightful and fulfilled the objective of exploring the lived experiences of the parents in what was described as a prolonged and at times emotionally frustrating and painful journey towards getting their child home. The overwhelming sense of living with uncertainty taken together with the descriptions of multiple transitions culminated in the title for the findings chapter of **‘Transitions of Uncertainty’** which ultimately captured the essence of their time caring for their hospitalised child.

The findings present numerous themes and individual descriptions revealing the difficulties encountered by the parents relating to their child’s admission and centred around the uncertainty faced due to the child’s critical illness and resulting transfers between hospitals, the uncertainty regarding the future and complex dependency of their child and finally the changes the parents experienced in caring for their child in hospital. The key findings have been grouped into the following four main themes:

1. ‘Going in to the Unknown’
2. ‘This wasn’t what we wanted’
3. ‘Safer at Home’
4. ‘Clawing every little bit back’

A diagrammatic representation of the parents’ journeys detailing the main themes and sub-headings is presented in Figure 1.

Figure 1: Diagrammatic representation of the study's findings detailing the main themes and sub-headings



The titles for the four main themes came directly from in–vivo material obtained from the parental interviews with each being a direct quote used by a parent to describe a particular aspect of their experiences. In keeping with the analytic approach taken, each main theme had a number of sub-themes and a full list of these with related key words and phrases have been included in Appendix 7.13. Each theme describes and interprets the accounts of the lived experiences and is illustrated using direct quotes taken verbatim from the interviews thereby substantiating the work and ensuring the reflective descriptions increase the trustworthiness, validity and credibility of the study.

4.1.1 Main Theme 1: ‘Going in to the Unknown’

‘Going in to the Unknown’ represents the findings with respect to the child’s initial deterioration in health, ensuing critical illness and the related experiences of the parents during the child’s admission to intensive care. It predominantly considers the uncertainties and associated emotional impact arising from their child’s illness whilst also considering the anxieties experienced relating to their child’s hospitalisation. Separated in to two sub-headings of **‘Uncharted territory’** and **‘Mixed Messages’** this first main theme depicts elements of the emotional and distressing journeys from initial admission to eventual discharge home.

The descriptions in **‘Uncharted territory’** represent the findings with respect to the child’s admission to hospital and the multiple transfers arising from changes to their health status. It also considers the related emotional impact and turmoil experienced by the parents when faced with their child’s critical illness. The section titled **‘Mixed Messages’** considers the parents’ experiences of communication and highlights examples of inadequate, inconsistent and contradictory messages emanating from healthcare professionals and provides descriptions of unsupportive encounters and interactions which resulted in conflict between the parents and staff.

4.1.1.1 Uncharted Territory

During the interviews the health and well-being of the children featured prominently in the experiences of the parents as they witnessed their child's condition deteriorate and as a result were admitted to the neonatal (NICU) or paediatric intensive care units (PICU). The families recalled the events surrounding their child's admission with all of them experiencing significant emotional turmoil and using strong and emotive words and phrases such as '*petrified*' and '*it felt like our world had fallen apart*' to depict the stress and emotion felt. Some children were diagnosed with life threatening conditions requiring urgent life-saving interventions such as Extra Corporeal Membrane Oxygenation (ECMO). ECMO involves using a machine to oxygenate blood via an artificial lung (membrane) outside of the body (extra corporeal) when the heart or lungs are not working effectively. For other children there was uncertainty regarding the underlying cause of their illness or diagnosis which added to the stress and anxiety of the parents. For all parents there were times during their child's admission when the overriding fear was whether their child was going to survive and on more than one occasion parents recalled being told to '*expect the worst*', with some wondering how long they could cope with the uncertainty and others remembering all they could do was watch and wait, not knowing what the outcome would be:

Mother (001): I remember those days when we are on CICU and he wasn't improving and I was standing there every day and seeing him, time after time being bagged, and go floppy, and I know just feeling like... when does this ever end?

Many of the parents lived through weeks and months lurching from daring to hope for their child's survival to experiencing setbacks and delays which they felt would never end. Parents spoke of how at times they would be preparing for the worst to then have a day when good progress was being made which then gave them hope for the future. One father described how difficult it was to manage and cope with the uncertainty on a day to day basis:

Father (007): Literally you were just sat on a rollercoaster every single day... You know on the 'Smiler' at Alton Towers and you're going up and down, up and down, up and down. And we had more downs than ups.

Other parents alluded to navigating this 'rollercoaster' of uncertainty and spoke of only being able to live their life on a day to day basis, coping with the immediate duties of caring for a critically sick child, whilst not being able to plan for the future. Families described a variety of different coping strategies to deal with the emotional upheaval and uncertainties they all faced. For some they felt they could do nothing more but just get on with the situation they found themselves in, yet when they looked back on their experience they questioned how they had survived.

Mother (006): You think how did we go through that? (Laughs)

Interviewer: And you cope at the time... but maybe you can do nothing other than cope at the time.

Mother (006): No, you have no choice.

Other parents demonstrated coping techniques such as using milestones to help them through their journey one stage at a time.

Mother (003): we had these milestones in our head. If we got past 48 hours... brilliant. If we get past a week... Even better.

Father (003): and then between a week and two weeks it's kind of repair territory (surgery). So that was great.

Often the parents spoke of their partners providing them with the emotional support they needed which helped them to cope through their difficult and emotional time on the units. They described having to 'bounce off each other' often finding that one day one of them would be strong and provide the much needed support only to find the following day the roles reversed. Parents also spoke of trying to hide their emotions and portraying a picture of being able to cope and spoke of holding themselves

together in public only to crumble when they were in private. Despite some of the parents identifying a lack of emotional and psychological support many spoke very highly of the comfort and support offered by members of staff including doctors, nurses and in particular nursing staff on the neonatal unit and a play therapist on PICU:

Father (006): The play specialist was brilliant. Especially at the really hard times when you first get told and all the rest of it

In spite of being provided with some support parents also commented about the lack of privacy on the intensive care and high dependency units and how they struggled to find anywhere to have some time to themselves to gather their emotions:

Mother (001): I found it quite difficult that the environment is so public. And I think that is really difficult.... It's difficult that there isn't anywhere for space. If you are just like having a bad moment... just to go and close the door.

In addition to the lack of privacy many of the parents described the inadequate facilities on some of the units which impacted on them both emotionally and psychosocially such as the lack of a seating which would enable them to sit together:

Father (001): Well yes, you know quite often one of you would sit in the chair, the other one would be stood on the other side. You know we couldn't like sit together side by side with our arms around each other with [child] on our lap because it's physically impossible. And even when you're in the same room you couldn't feel like a family, well you do feel like a family but you don't get that - you can't do it. You know like a little two seater settee would be... it would make the world of difference.

Although the overriding descriptions of emotions were of turmoil and anxiety as they transitioned through the uncertainty, the parents also spoke of joy and happiness as

they described their children surviving the critical stages of illness, which gave them hope for the future.

Father (001): we knew that we weren't at the end of the road but, we'd suddenly got a massive glimmer of hope whereas you know, before that it was all quite stressful wasn't it (to wife) and we didn't quite know where we were going with it all.

Notwithstanding the diagnosis, due to the serious nature of the underlying conditions the decisions taken by the clinical teams caring for the children was that they all required invasive long-term ventilation (I-LTV) via a tracheostomy to increase their chance of survival or to enable their recovery. This involved the children undergoing elective surgery for a tracheostomy to facilitate supportive ventilation on a long term basis.

Once the surgery had been performed the tracheostomy gave rise to heightened emotions for parents and signified a major life-changing event in the lives of the children and the parents. Whilst appreciating the tracheostomy served a primary function of protecting the child's airway it became an intrusion from both a practical and emotional level requiring the parents to adjust and adapt to enduring physical changes in their child and to learn new clinical roles and caring responsibilities:

Father (008): I think for me one of the interesting things thinking about it now... the thought of a) having the tracheostomy and b) [child] coming home with a tracheostomy, seemed to be... daunting is the right word. I struggled with it because it was accepting... it was another thing to accept on top of his injury and for me then it was accepting the fact he had significantly changed... and... it was much more of a physical change to him...

Mother (008): ...you are preserving his life with that tracheostomy and that is what that is there for.

Another important consideration associated with '**Uncharted Territory**' related to the experiences of the parents regarding the multiple transfers the children were subject to during their admission and the uncertainty arising from the moves between hospital units. Whilst the child's admission to hospital was a feature spoken about by most of the parents what this study highlighted as being more exceptional was the number of transfers experienced and the emotional impact and psychological effect these moves had on the parents.

There were a number of different transfers described in the interviews, sometimes they involved an intra-hospital transfer (within the hospital) whilst others experienced inter-hospital transfers as they were moved between hospitals, some of which were geographically a significant distance from the original hospital and the family's home. Furthermore the need for transfer was deemed necessary for a number of different reasons. Some parents described being moved from the neonatal unit to the paediatric unit once their child was considered to be too old to stay on neonatal intensive care, whereas other parents spoke of their child being transferred from one hospital to another because of the treatment they required such as ECMO or cardiac surgery which could only be provided at the specialist unit. All families described experiencing multiple transfers between individual units and hospitals with three moves being the least number of transfers experienced for the families in this study. Of note, one family described their child was cared for in five separate units during a nine month period, in four different hospitals, which were situated in three different cities.

Transfers between hospital units and individual hospitals is often required and accepted by clinicians as being necessary to provide the correct level of care the patient requires in accordance with the seriousness of the condition. These transfers are often perceived by healthcare professionals to be routine and can be taken for granted as patients are stepped up or down to receive the appropriate level of care. In contrast parents found this type of situational transition to be highly traumatic and caused significant stress and anxiety often due to the uncertainty associated with the move.

When talking about their experiences of being transferred the parents used descriptions such as '*awful*' and '*horrendous*' and on more than one occasion, transfers were described as '*daunting*'. Some stated it felt like they were '*going in to the unknown*' and '*having to start afresh*' while others spoke of how they were surprised at the unexpected differences between the various units particularly the ethos relating to the exclusion of parents from ward rounds despite them being in the same hospital trust all of which added to the parents levels of stress and perceived lack of control.

Negative feelings were often expressed in respect to the lack of communication the parents perceived between the different clinicians involved which gave rise to feelings of frustration and annoyance. In one example a mother spoke of her anger at the time when her child had to be transferred to a third hospital to be reviewed by a specialist consultant. When the doctors suggested within minutes of their first meeting they were going to have '*scrap everything*' and '*start again*' the mother recalled questioning his ability to make such a decision without having met her child before:

Mother (002): And I was like 'you're not starting from scratch. You're not going to do everything over another 4-6 weeks to tell me that she needs a trache, when we should have had a trache yesterday, I want her home....' And I just remember thinking and I said to him 'who the hell are you? You've never even met her'. It was just all... it wasn't a good meeting.

This demonstrated how sometimes healthcare professionals inadvertently used phrases and terminology parents found distressing. However, this may have been in part be due to the parents enhanced sensitivity to their child's critical illness and uncertain prognosis, yet illustrated how an insensitive choice of words impaired the parent's ability to manage the stress and uncertainty brought about by the transfer.

Another family, although acknowledging they understood why their child needed to be transferred, spoke about how disturbing the experience was and how the uncertainty of not knowing what to expect had an effect on them. They defined it as more

unsettling as they had been resident on the unit with their child for a considerable time and consequently it had become like a 'home' for them providing a level of comfort and security.

Mother (003): 'We had like lived there, moved in there... We were settled in... we had obviously been there for 4 weeks. Yeah it was horrendous but... we'd get our own room, we were settled, but we were going in to the unknown and we were starting afresh again.'

The mother continued to describe how the move to the different unit affected her trust in the staff and her faith and confidence with them in caring for her child and consequently how this then had a bearing on how she felt about leaving her child.

Mother (003): and you lose trust. You had built all the trust up... and I didn't trust anyone and I wanted to meet everyone and spend some time with them before I left.

Other parents suggested the experience of being transferred left them feeling abandoned and in disarray with some describing how they desperately wanted to return to the comfort and security of the place they had come from, being cared for by the people they had built up a relationship with and had so much trust in. One mother emotionally described how she returned to the neonatal unit to speak to the consultant after her baby had been transferred to the paediatric HDU for ongoing care as he was considered to be too old to remain on the neonatal intensive care unit. As she was unhappy with the care he was receiving she described going back to see the consultant to see if he could be transferred back. Although the mother was told her child would not be able to transfer back she reflected on how the supportive the doctor was and how well he handled the situation treating her with respect and helping her come to terms with the transfer.

Mother (007): and I said 'I want you to take him back' because this is what they want to do. So he listened to the whole story of what they'd

done and... He goes... he was so upset himself... He was amazing... and he goes... 'I'm here to comfort you and you've told me everything' and he goes 'I can't take him back because once you leave neonatal that's it you can't go back in, you can never go back in sadly.'

Unfortunately the way other healthcare professionals handled the transfers was not always seen to be as supportive with parents expressing they felt some doctors did not appreciate the moves had a major impact on the parents and family and caused unimaginable stress:

Mother (007): But you know that stress was huge and I said to the doctor 'I don't think you actually realise... Put yourself in my shoes... How would you feel?' And that's what I said to her, I said 'I don't think you realise how stressful this is.'

One of the main areas of concern described by the parents was the step-down from the intensive care unit (ICU) to high dependency (HDU) care. Transfers from ICU to HDU were one of the most stressful experiences parents faced during the child's hospitalisation and for some caused feelings of distress similar to those described at the time of their child's admission. Parents were uncertain of what to expect and they recalled worrying about what the move would entail, not knowing the difference between the units and what this would mean for them and their child, leaving the support ICU provided at a time when they are often physically and emotionally exhausted:

Mother (005): because I didn't know that would happen.

Father (005): ...they said because it's a high dependency unit don't worry. Well we were like... what's a high dependency unit?

Parents also spoke of a lack of recognition by some of the nursing staff of the impact of the transfer from ICU. A mother described following a transfer from ICU to HDU they spoke to the nurse about what her involvement would be and enquired about the care

their child would receive, but the response demonstrated a perceived lack of understanding and demonstrated to them she really did not appreciate the effect of such a move.

Mother (005): And I said 'how often do you come in, do you stay in here?' and she kind of looked at me as if to go 'have you really just asked me that?'

As the parents did not know what to expect they suggested the provision of basic information would have enabled them to be better prepared and reduce the uncertainty they felt as they were left to find out the detail for themselves:

Father (005) ...If someone had said look you know, one nurse it's like a 3:1 ratio, he will have hourly obs (observations), he will be here, and somebody will come in to monitor him. There is a monitor at the end which is on the nurses' station. You can ring up at any time... we had to sort of find these things out.

Whilst parents were aware the move to HDU signified their child was getting better it still evoked a significant reaction for some. A father recalled his anxiety regarding the transfer from ICU and although he recognised this was a positive step towards his child's recovery and discharge, he felt very anxious and stressed about the move due to the fact HDU had a reduced nurse to patient ratio. He described struggling with his mixed emotions and whilst he was glad his child no longer required one to one nursing care, he recognised in many ways he wanted this to continue due to the reassurance this level of supervision provided. However, he also realised this level of care would have meant his child was still very sick.

Father (001): I think transitioning from one to the other wasn't the most reassuring because you're dropping from like a one-to-one to a 4:1 or whatever, but I think that getting used to that lower level of dependency... you almost... almost the need for him to have one-to-one

is almost too reassuring in some respect. But obviously you don't want to have that, but the fact that he gets it was quite reassuring but when you lose that then... that's suddenly quite nervy.

Another mother described the move to HDU as a '*massive shock*' as she had not been prepared for the difference in care between the two units. Consequently she became very anxious about leaving her child and feared for his safety without the constant presence of the nurse at the end of the bed.

This 'transfer anxiety' has been recognised in other studies that have considered the effects of transfer on patients and their carers from ICU yet even transfers within a small unit from the open ward to a cubicle caused parents some anxiety and resulted in significant emotional distress. This distress was shown to have a lasting effect as following the child's discharge home one mother described how she continued to link his isolation in a cubicle with her not wanting her child to be on his own at home:

Mother (007): I guess that's why I'm quite protective over him. I don't like him being on his own much during the day and obviously we are always there anyway and the nurses are there, but I just think oh the poor boy was on his own in that room and you just think 'oh God'.

Although recognising her anxiety was possibly contributing to her continued need to protect and watch over her child, her account shows some insight into the concern and psychological impact that leaving her child alone in hospital had on her.

Despite the critical nature of the child's illness, all of children, whose parents were involved in this study, improved sufficiently during the admission to reach a level of health and medical stability considered fit enough for them to be discharged from the hospital and cared for at home. In planning for home it is recommended and widely accepted by healthcare professionals that the child should have a phased discharge to prepare the family for the reality of caring for their technology-dependent child. This involves the child initially spending a day at home, followed by a night at home with all

the equipment in place to ensure they had everything they needed to safely look after them prior to their final discharge. This approach was very much encouraged by the medical and nursing staff and very much appreciated by some of the parents as they began to experience the complexities of caring for their technology-dependent child. However, despite wide recommendation the phased discharge was also felt to be extremely challenging by some parents with comments suggesting how psychologically difficult it was to be allowed to go home only to have to return to the hospital and stay again for days and sometimes weeks, whilst the home care support was finalised. Parents described how they '*absolutely hated it*' as once they were home they did not want to take their children back. One mother spoke of how emotionally hard it was for her to go back to the hospital once she had experienced being at home with her son:

Mother (008): That to me is harder than just coming home. Because you have had him and you've had that experience of being at home... It was heart breaking.

This emotional turmoil linked to the phased discharge continued for some of the families for many weeks and as long as 10 weeks in one case. A number of the parents recalled coming to a decision they no longer wanted to keep going back to the hospital when they reached a stage where they felt sufficiently prepared to keep their child at home for longer than just one day or overnight. Sometimes this decision was met with agreement from the hospital staff, yet on other occasions the parents described the clinical team expressed concerns that it was unsafe to do so and felt that they asserted a strong paternalistic control over the situation, clearly advocating the parents should wait until they deemed ready. Other families also described similar authoritarian behaviour of the professionals with one mother stating that despite their child being medically fit for discharge and both parents being fully trained and signed off as being competent to look after their child's tracheostomy and ventilation needs she felt as though the nurses were actually putting up barriers to prevent them from going home.

Mother (001): I really did feel that there was a period of a week or two where I felt that the nurses on the ward were putting barriers up, and I don't think they were doing it deliberately, but I felt that... I think, had I let it, I think I could have allowed them to undermine my confidence in looking after him. It felt as if they were questioning that whether we were able to... whether we were safe to take him home.

In addition to the parents dislike of the phased discharge the families with older children on I-LTV spoke of how their children also hated this part of the preparation for discharge often showing signs of physical and emotional distress. Parents of two of the three older children in the study recalled the children were initially 'scared' when facing the daunting prospect of leaving the safety and security of the hospital environment, but once they had been home they then became distressed at having to return to the unit. One family vividly described their child's physical reaction to knowing she was being taken back to the hospital. Despite feeling initially she was so institutionalised that she disliked leaving the ward environment they recollected the emotional and physiological impact it had on their child when returning to the hospital when she began recognising the journey back:

Mother (006): ...and having to take her back... she used to get so upset, her sats (oxygen saturation) would absolutely drop, her heart rate would go up and she would know as soon as we would go...

Therefore although it is both well recognised and accepted that a phased discharge is advocated to prepare the families for the enormity of caring for a child on I-LTV at home, it is also important to consider the negative aspects this places on the family and the child.

Together the admission to ICU, transfers and phased discharge caused parents significant stress and anxiety and these findings highlight the importance even a small move can have on the family and suggest professionals afforded insufficient attention to transfers particularly at times when the children were moving down from intensive

care as the child's condition improved. Participants mentioned a lack of communication and support and how they wanted additional information to help them towards coping with the uncertainties arising from their child's illness transition particularly with regard to the transfers experienced. This leads on to the second sub-heading of 'Mixed messages' which focuses on findings relating to aspects of communication.

4.1.1.2 Mixed messages

Effective communication between healthcare professionals and parents is paramount and should be fundamental to the care and management of the child and family whilst they remain in hospital (NMC, 2015). However, this study presented many descriptions of inconsistent information and inadequate communication which were a major source of parental stress and contributed to the uncertainty experienced particularly when related to the treatment and care of their child. Although the majority of the parents' descriptions told of experiences where they felt the communication and information was less than ideal, it is also important to note there were also recollections of healthcare professionals exceeding the parents' expectations and demonstrating excellent communication skills providing valuable and much needed information.

Communication regarding clinical care and management was of particular importance with all parents describing incidents where they felt communication regarding their child's condition and treatment could have been better. One mother recalled the time when the possibility of her child needing a tracheostomy was first discussed recognising they felt insufficiently prepared and perceiving a lack of understanding by the Doctor of how significant the discussions were:

Mother (001): And nobody explained anything about... we had quite a bad experience actually of being introduced to the trache... they brought [Consultant] down to see us and he basically just spoke to us as if it was already a done deal, it was like we're doing it tomorrow... really, really flippant. Not recognising that it was a big deal....

At other times parents highlighted a lack of consistency in the clinical management of their child, leading them to feel uncertain about healthcare plans which affected their trust in some of the clinicians. Some of the inconsistencies occurred due to the organisational and staffing arrangements as consultant cover on PICU changed on a frequent basis. This change in medical leadership often resulted in changes to planned clinical care due to individual experience and practice causing a great deal of uncertainty and anxiety for some of the parents. At times this also resulted in conflict with one mother remarking on how she felt she had to challenge the clinicians as she believed the change in care wasn't what had previously been agreed:

Mother (002): And I did... I had argument after argument because that wasn't the plan.

The same mother went on to describe how she frequently experienced the intensive care consultants making a decision regarding her child then finding another consultant had changed it within a very short time frame. This again led to feelings of mistrust and frustration and clearly demonstrated why the parent felt the need to contest the decisions the individual clinicians made, again adding to their stress. In addition the mother also felt the different approaches to care had a detrimental impact on her child's health.

Mother (002): And a few times the Consultant did come and apologise to me and say 'okay I've stopped it we going to go back to what I said' on whatever day. But it's too late by then because you've messed around with medication three days in a row or whatever they'd done.

In addition to the perceptions of inconsistency, the lack of communication was also raised as an important issue by parents. This became particularly significant when there was more than one clinical team looking after their child. One father spoke of how he and his wife were often used to help inform the other clinical teams of progress and decisions regarding their child's care as the clinicians appeared to not

communicate directly with each other. When the parents were unable to answer the clinician's questions it caused them to feel inadequate and anxious:

Father (005): I felt there was a little bit of a lack of communication between the cardiac team and the respiratory team. I felt like they would ask us stuff and I wouldn't know how to answer some of it and I kind of felt that maybe it should've been in his notes. But I know the notes by then were quite epic, but I felt a bit stupid not being able to answer to some of the questions you know.

Parents also voiced concerns with regard to the level of information they were given about their child's clinical condition. This was most notable in the early stages of admission when the parents were unfamiliar with their new situation. Some reported difficulty in understanding the clinical information and struggled to take in what was being said to them. This was expressed as either being due to a lack of comprehension or due to the fact what they were hearing was overwhelming, demonstrating the parents' ability to understand information at times of emotional distress was undoubtedly affected. Furthermore it was recognised healthcare professionals did not always take this into consideration when they were communicating with parents. Evidence of this was demonstrated by parents describing clinicians speaking in a language 'way above their heads' with some suggesting they felt intimidated by the technical jargon. Even the routine use of terminology healthcare professionals often take for granted had a major impact on the experiences of some of the parents especially when life changing decisions were being discussed. Phrases used frequently by clinicians' invoked feelings of confusion for parents as they were uncertain what they meant and the implications these held for them. One father remembered the consultant talking about his child needing 'continuing care':

Father (006): I remember him saying 'Right, we've got to get continuing care involved.' I hadn't got a clue who continuing care was. That's the first thing... Continuing Care Team! Nobody knows what that is!

Conversely other parents described clinicians speaking to them in a language too simplistic which was also a source of frustration as they wanted to have involvement in the discussions at a level where they felt they could contribute. Yet they felt they *'weren't credited with the intelligence to be able to really talk about what was going on.'* Again these findings emphasised the importance of healthcare professionals communicating in an effective and open manner using language appropriate to the parents' level of understanding but taking in to consideration the context of the situation.

Some parents recalled other doctors were better at *'getting it right'* describing conversations involving critical and life-threatening situations where they felt supported, informed and at ease, which helped to allay some of their fears. This was evident when a mother spoke of the critical care transport consultant coming to transfer their critically ill child for Extracorporeal Membrane Oxygenation (ECMO) treatment.

Mother (003): we felt really at ease and actually... he had the right tone again and he had a couple of jokes like ... and looking back to think, 'oh my god', how serious it was and he was joking about but actually at the time it put us...

Some parents recognised the communication with the medical staff changed in accordance with the critical nature of the child's condition. They found as their child's condition stabilised or improved and there were less changes made to the child's treatment they were involved in less dialogue with the clinicians. One father spoke of the difference between two of the intensive care units where their child had been a patient. Despite the same medical staff rotating between the two units he observed a difference in the amount of communication and time the clinicians spent talking to the parents regardless of the fact they were both intensive care units and the need for communication was still highly desired.

Father (003): At [Hospital 2] they would sit down and talk to you... probably on a daily basis. At [Hospital 3], I can probably remember 2 or 3 times when actually a consultant sat down and spoke to us. It was like the same consultant had a different attitude, wherever they were. It was strange.

The perceived difference between the two units led to the family describing how much more at ease they felt with the staff that interacted more frequently with them. They described how their feelings of trust changed to mistrust and the relationships with staff began to decline when they moved units, resulting in feelings of suspicion and the parents perceiving negative attitudes towards them from staff describing it as '*parents against nurses*.' Similar findings also demonstrated how the attitudes of parents changed towards professionals when communication was perceived to be inadequate.

Another significant area of parental concern and distress relating to communication was whether the parents were allowed to be present during the ward rounds on the intensive care units. Being excluded from the ward round was a frequent subject of discontent described by a number of parents who felt they were being excluded from the decision-making and plans for their child's care at a time when, unquestionably they felt they should have been involved. Not only did this mean they were being denied the opportunity to hear discussions first-hand, but also it meant the parents were reluctantly separated from their child for lengthy periods of time as the ward rounds were reported to take up to two hours. What is more the parents faced further uncertainty as the exclusion appeared to depend on the preferences of individual clinicians which consequently resulted in parents not knowing on a day to day basis whether they would be allowed to stay with their child whilst the ward round was conducted.

Mother (003): ...because some doctors would allow you to go in on the ward rounds and some wouldn't.

This unwilling separation accommodating the routines of individuals on the intensive care unit resulted in the parents not only being excluded from decisions regarding their child but additionally meant they were unable to contribute to clinical discussions and highlight, for example, when they noticed subtle changes in their child's condition which they felt went unnoticed by the healthcare professionals.

Mother (001): And it... it felt like by not involving us at the ward round and not involving us in those discussions, we didn't get the opportunity to raise things that we were noticing in him.

Other parents also felt they were able to detect and recognise minor changes in their child which they perceived were thought of as insignificant or unimportant by healthcare professionals but which later went on to be relevant. Parents put this down to the fact they knew their child best and could see how they were coping and responding to treatment:

Mother (003): We just knew him. We just knew that he was definitely ready for it. It's like now with the trache he's got that for another three or four weeks. We know he's ready (for it to be removed).

Yet as one father succinctly described the concept of families being adequately involved in their child's care was not at the forefront of their experiences and was felt to be lacking in the approach taken by the staff on ICU:

Father (001): They used to say that all you need to do is ask for the consultant to come and speak to you... and it's like well actually that's the wrong way round.

In addition to being excluded from the ward rounds there were times when parents felt they were deliberately ignored and almost ostracised by the staff on PICU with parents perceiving that clinicians 'disappeared when the parents turned up...' or talked about their child in a manner in which they again felt excluded:

Mother (001): even to the point when sometimes when if they had to come round when we were there they would step away from the bed and talk about him under their... you know in hushed voices. And I'd be like 'that's my baby you're talking about... umm, I can't really hear properly.' And I remember initially I felt like I wasn't supposed to listen.

This emphasised how the parents felt as though they were intruding on private conversations yet the subject of the discussion was their child. A further example of this occurred when the doctors were preparing to move their child to another hospital with the parents describing they only knew the move was happening by overhearing the doctor speak to the nurse. What was particularly disturbing and unacceptable for them was even though they were present in the room, the doctor spoke to the nurse without addressing or even acknowledging them. This caused significant distress showing how exclusion and being ignored led to parents feeling undervalued.

Mother (001): We found out he was being moved by overhearing one of the doctors come and ask the nurse to prep him for a move. It's just not... you know... it's not good enough. And I think... we were... at the end of our tether.

Father (001): But no one said anything, it was just that - even though we were in the room, the doctor spoke to the nurse next to us and said, "can you just prep him for the transport"... and then walked out and didn't speak to us.

Additional examples were given by the parents emphasising how inadequate communication caused them substantial distress and anxiety. Parents described how they had learnt about significant health details regarding her child by overhearing conversations between clinical staff.

Mother (001): We were not told things for example that they had picked up in an x-ray that his ribs were broken... and nobody told us. And I

overheard, I overheard it from a nurse one day. And it turned out that they'd picked it up a week and a half earlier.

They also gave examples of when they described unnecessary worrying when it transpired a scan had since been performed without the parent's knowledge and the results had come back as being normal. Due to fact the parents were anticipating the scan still needed to be done they felt they were *'still worrying about something that we needn't have been worrying about.'*

Following the multiple examples of inadequate communication, a mother went on to describe she felt it was more than just a lack of communication and sensed some of the staff did not value the parents input and this was apparent in the underlying culture of the unit:

Mother (001): 'but on CICU the doctors – it felt that they didn't recognise that the parents were important ... and to be fair... probably some of the nursing staff as well.'

The issue of parents on intensive care feeling they were being ignored and undervalued was not unique to this family, yet there were other descriptions in direct contrast to those above as parents spoke of their experiences in which they recalled the communication and their involvement as being much more positive. This was often found when the parents were recounting their experiences of time spent on the neonatal unit where they seemed to recall there to be a stronger sense of family-centred care, and gave illustrations of where they felt valued and included:

Mother (001): The first thing they do is ask the parents how they feel and how they think their child is.

The constructive ethos and culture of the neonatal unit was something a number of the parents commented on especially when they were comparing the care they received after being transferred to another unit.

Despite these positive recollections, parents mostly recalled experiences of conflict and more unsupportive exchanges with staff. And whilst there were very few descriptions of severe conflict, there were situations where parents thought they had been chastised and spoken to in an inappropriate manner which resulted in relationships deteriorating between themselves and the staff involved. This was illustrated when one parent on ICU raised an issue with the nursing staff regarding a lack of communication. The nursing staff were reported as responding to the criticism in the presence of other parents, where it escalated to the point where the families involved felt a need to support each other and as a consequence were accused by the nurse of '*creating problems*'.

Mother (001): we were not part of the conversation, we were just in the room... she turned round and went ... 'and you two are just as bad.' And I just went... 'Pardon!' And she had Claire in tears and I felt the need to defend her and I was like 'Claire is not being picky, she is just asking for some basic information.' Actually she hadn't even complained, she'd just said, 'in future if people could tell me that this has happened.' And we ended up in this debate and then we were accused, 'this is the problem when we put you in a room together you start creating problems that aren't there' and we were like ... 'No, what happened is we had a conversation about something, a real problem that is existing on this unit' and that we were... I would go as far as to say she bullied Claire that day.

Other parents also perceived a lack of respect from some of the nursing staff but made allowances for this suggesting it was because they had been in hospital for such a long time.

Father (003): yes and the way some of them spoke to us as well, I mean... I understand that we would have been in the hospital for six

months... but you would come away and you would think 'did she really speak to me like that?'

This description raises an interesting concept of how the parents perceived the attitude of the nurses changing towards them and how they considered this may be in part due to the length of time they and their child had been on the intensive care unit. Although the family may have tried to reason this was acceptable, it demonstrates professional nurses acting in an unprofessional manner and outside of the Nursing and Midwifery Council (NMC, 2015) Code of Conduct. Whilst it is important to acknowledge that other research has shown there are times when parents speak in ways clinicians would find unacceptable, what should be remembered is these families were all in highly stressful situations and faced their child being critically ill and in hospital for many months, rather than being at home with their families. Although this does not always excuse discourteous behaviour it should be part of the consideration when caring for these families and as research has shown, much of the conflict arising in the critical care environment is because of poor communication.

This section on '**Mixed messages**' has considered the parents' experiences of communication during their child's admission and has highlighted examples of how inadequate exchanges and inconsistent messages contributed to the stress and anxiety felt by parents. It has demonstrated how pressure felt in the intensive care and high dependency units contributed towards an atmosphere of tension and provided descriptions of unsupportive encounters which resulted in conflict often arising due to sub-optimal communication. However, it should be emphasised that not all the communication was sub-optimal and parents also described examples of excellent practice.

In summary the descriptions in this chapter titled '**Going in to the Unknown**' have identified some of the findings relating to the children's illness and encapsulated the journeys of uncertainty experienced by the parents. Although unique to them individually, many of the findings described are in keeping with previous research

exploring the experiences of parents who have children admitted to hospital and more specifically critical or intensive care as they feared for their child's survival. However, what was more exceptional to this group of parents was the number of transfers experienced and the enduring emotional upheaval accompanying these multiple transitions. The findings highlighted suboptimal communication and while there were illustrations of good communication these did not feature as prominently in the descriptions of experiences encountered during their time in hospital.

The next sub-chapter titled '**This wasn't what we wanted**' will consider the hopes and fears regarding the life-changing events experienced by the parents as a consequence of their child's illness and need for I-LTV.

4.1.2 Main Theme 2: 'This wasn't what we wanted'

The second main theme titled '**This wasn't what we wanted**' refers to the experiences of the parents as they began to realise they were moving to a new unfamiliar world caring for a child dependent on life-supporting technology. This main theme has two sub-headings of '**Uncertain Futures**' and '**Information & Signposting**' providing insight in to the uncertainty experienced by the parents following their child's commencement on I-LTV and the connected hopes and fears for the child and family in the future. The first sub-heading '**Uncertain Futures**' presents findings relating to the changes in the parents previously anticipated world with the section on '**Information and Signposting**' revealing descriptions of where the parents found information on what the future may hold caring for a child on I-LTV.

4.1.2.1 *Uncertain Futures*

Both the tracheostomy and subsequent long-term ventilation signified life-changing events requiring parents to modify assumptions about their world. Parents spoke of the discrepancy of what they had hoped for compared to the reality of what they now faced. They revealed lost hopes and dreams from anticipations of becoming a 'normal' parent, where thoughts of changing nappies had been replaced by the thoughts of changing tracheostomy tubes. A mother spoke of her reluctance to be introduced to other babies with tracheostomies, not wanting to accept the new reality in which the world of caring for a baby with a tracheostomy was seen to be the norm.

*Mother (006): it's just was... this wasn't what was supposed to happen.
We were just supposed to have a baby...*

So when you're in the hospital environment, a trache is very normal and they kept saying come and see some of our other trache babies on the ward. And I am like... I don't want her to be a trache baby, I just want her to be a baby (laughs). And I remember... I just thought... I don't know... just that... I don't want this... this wasn't what we wanted.

Some of the emotional turmoil experienced also related to the uncertainty of what the future held for them and their child. To some parents when they were first introduced to the fact their child was going to require long-term ventilation they were initially unclear of what 'long-term' meant:

Mother (001): I think most parents that I've spoken to 'long-term' means forever. And that's what they think it means and actually it doesn't mean... It's just about being clear that it doesn't necessarily mean forever.

Not fully understanding the implications and as a result of not being provided with sufficient information the parents feared for the future of their child and imagined they would have to remain in hospital or at best would have to replicate a hospital like environment in the home. The same mother became very emotional when she spoke of being told her son would need long-term ventilation and how this conjured up a vision of him spending the rest of his life in a room attached to a ventilator.

Mother (001): because I think the fear is, that you're basically saying, right my child is not going to have a life when you agree to have a trache and I think that when we first told about the trache, it wasn't the trache itself, it was the fear, it was the vent (ventilator), it was he was going to be attached to a vent...

Father (001): ...well I can remember you thinking that you were just going to spend his time in his bedroom... and wondered what his quality of life would be and it's like... soul destroying.

The parents recalled feeling guilty and questioning the decision they had made regarding starting the treatment they believed would save his life due to the uncertainty of what the future held and the lack of information they had at that stage:

Mother (001): I was envisaging that he would never go to school, he would never play with toys, you know really, basically... but like he has

no life or quality-of-life whatsoever and I remember thinking, it sounds awful but I remember at the time thinking if this is the life we have signed him up to I feel really bad that we wanted to save him.

However, they reflected that after their child had been established on the ventilator and they understood that long-term did not automatically mean forever they began to appreciate the reality of what life would be like which was very different to the world they had imagined and feared. They also spoke of how little information they had been given at that time and suggested how during the first conversation regarding I-LTV parents should be provided with sufficient detail for them to understand that *'life can still go on with a baby with a trache on a vent'* allowing them hope for the future.

The tracheostomy itself became a symbol they were leaving the world they had previously known, transferring in to an unfamiliar world of assistive technology leaving them uncertain about the future. Some parents recalled the moment of realising this was going to be a permanent or long-term requirement for their child and brought new awareness the parents and child were moving to a new life requiring adjustment and adaptation:

Mother (006): And then tracheostomy, you're suddenly thinking, well that's going to leave a scar and that's going to be permanent and I think it was that sort of dawning that actually this is something more.

Families also spoke of struggling with the concept of accepting the child they had previously known had changed, in some cases forever, with one father acknowledging the reality and enormity the tracheostomy signified. He recognised in addition to the physical change brought about by the tracheostomy it became a visible reminder of the permanent loss of the child he had known which he found difficult to come to terms with.

Father (008): I struggled with it because it was accepting... it was another thing to accept on top of his injury and for me then it was

accepting the fact he had significantly changed... and it was much more of a physical change to him. Until he had had the trache he looked like... still looked like Daniel... And all of the sudden to have that very permanent thing... and think then he will be at home and he will have that machine going (makes whirring noise) and all that going on, that made it a much more final thing for Daniel. And then to realise... yes this is now Daniel not previous Daniel... yes that was a bit of a... that took some time to accept that really.

Sometimes conflicting advice also had major impact on the parents' hopes and fears for the child's future. One family spoke of being in the intensive care unit many miles away from their home when they were told by the consultant their child would need to have a tracheostomy and as a result would not be able to talk or eat, which they later found out to be untrue.

Father (004): And they say he won't be able to eat, he won't be able to talk and it comes to a situation where excuse me... What is his life then? We brought him in here where everything was fine. Now you're telling me we going to take like a vegetable back home. Where he can't eat... say have to feed him through the tube... He can't talk.

As a result of this conflicting communication the family lost complete confidence in the hospital, with the father referring to this incident as one of the worst memories of their entire time in hospital.

Parents also spoke of the shock realising of what taking their child home on a ventilator actually meant in terms of the level of care their child would require and the additional support they would need to look after their child once they were discharged home.

Mother (008): I don't think it hit until I realised and we'd been home a couple of times, actually the level of care that the child tracheostomy

requires is constant and you can't physically... for him... go to the toilet without thinking can I hear him? What's he doing?

Moreover once they were home it became apparent their whole life would change and not only would it affect them and the siblings but their house and lifestyle as well.

Mother (008): You've got to change not just him coming home but your whole lifestyle and you've got to change how your house is and you've got to then discuss it again with [sibling] to say right okay this is how Daniel is going to be... you've got to adapt her to the changes and... (pauses) It is a lot and your whole life just completely flips. You don't realise and we're talking just the trache transition here... just that on its own, completely changes everything and it's not... it's not an easy change.

Furthermore families also spoke of the shock of realising they would need to have carers in the family home and for some this was going to be continuous throughout the day & night:

Father (006): I think the first thing was the shock that you going to have people in your house 24-seven.

Mother (006): And the shock of her coming home with a ventilator for me as well. It was... You're so involved in... right, she's intubated, she is on a ventilator oh she is on a trache, oh that's great news you can move out of ICU onto HDU and I think that dawning realisation that that's it...that's kind of as far as she was going to go and that we had to replicate that in our house I don't know if that sounds strange but... I think until [community nurses] came and sat in our room I hadn't really thought about having her at home.

Although the parents often spoke of feeling scared and frightened in relation to the early stages of their child's hospital admission, it became apparent this feeling even

after months and possibly years of their child being at home was still present for some of them and confirmed the continuing psychological impact of invasive long-term ventilation:

Interviewer: Can you remember when you stopped being scared?

Father (006): (Long pause) Erm... I don't know. I still get a little scared.

It's just that it's a bit more that I know I can deal with it.

Despite the initial fears regarding the future, once the parents became skilled in caring for their child they began to rebuild and adapt their lives and the normality of living with a child on I-LTV developed in to an understanding and belief that '*life can still go on with a baby with a trache on a vent*' (Mother: 001).

Parents spoke of tasks such as suctioning and changing the tracheostomy tube becoming second nature. Although parents described initial feelings of being '*daunted*', for some they described these feelings eventually changing to those of acceptance. Over time, and as they became competent and confident in the clinical procedures these became part of the routine care they provided. One mother described '*we suction him like we change his nappy*' and went on to describe the tracheostomy as part of his everyday clothes:

Mother (001): Because at the end of the day that is part of his... you know, clothing (laughs) you know. Like that's part of what he has to wear.

Other parents described how the trache and ventilator became a normal part of their everyday life and they had even started to forget the impact it initially had on them.

Father (006): because it does become normal. I think that... perhaps you don't see that it will just become part of your life and everything.'

Many also spoke of the concerns they had for the loss of normality and the '*dawning realisation*' life would no longer be what they had originally imagined of parenthood

yet these descriptions provide evidence of the families accepting and adapting to these major life changes and a new 'normal' emerging from the psycho-social transitions experienced.

4.1.2.2 Information and Signposting

Another important aspect concerning the uncertainty parents experienced related to the provision of information about their child's condition and the signposting preparing them for life at home with a child on I-LTV. Most parents described the hospital providing them with written information in the form of a booklet about the clinical aspects of caring for a child with a tracheostomy and ventilator, yet on more than one occasion the families referred to wanting more practical information they could access electronically on their phone, tablet or computer relating to what life would be like for them once they were home.

Mother (003): People don't want to read leaflets... It's no good. You need to be able to do it like on your phone or something.

One father mentioned they had received a '20 to 30 page document' containing tracheostomy information but that he had not read it although his wife's family had found it useful. Another father also mentioned the tracheostomy booklet they had been given by the ENT consultant but both he and his wife found it contained too much information suggesting it was 'too big, too much' and caused 'information overload.' Rather than being given information to read the families spoke of wanting to meet and speak to other families who also had children on I-LTV. Most of the families described meeting other parents either on the units or through being introduced to them via the hospital but whilst the majority found it helpful, sometimes the support and advice the parents offered frightened the families by talking of the realities and difficulties faced once their child was home. In addition to meeting other parents the other main source of support described as being very helpful was 'Facebook' with references made to the beneficial network of support available both day and night.

Mother (003): The tracheostomy Facebook page is amazing as well. I would definitely recommend that. That Facebook page is brilliant.

When asked about how they had found out about the Facebook page it became apparent it was either found through the parents' own volition searching the internet or through other parents advising them of the site. None of the families mentioned being informed by the nursing staff on the units or wards. They also expressed a desire for knowledge and access to this sort of information much earlier on in their child's admission and some as soon as there was a suggestion their child may need a tracheostomy. Yet for others there was a recognition too much information too early on may have been difficult to handle.

Father (006): I think I suppose if somebody had... say if you got a diagnosis and they got a video of a family at home with a child with a similar diagnosis. I think then that would have probably show up or highlight a lot of things that you don't think of, like you going to have continuing care and everything, you're going to have medical people involved in your life and all the appointments and stuff like that.

Mother (006): but would you want all of that? Would you want to do all of that at the beginning?

Nevertheless there was also recognition for some parents the information they accessed on the internet was quite frightening and perhaps was not the most helpful action to take especially when their child was critically ill or had recently been given a life-limiting diagnosis.

Father (006): the worst thing you do as a parent is that you start googling stuff.

The most overwhelming desire expressed by the parents was a need for practical information in the form of a DVD or short film they could access whenever they wanted and showed them life with a child on long-term ventilation could go on with

some normality. By being able to see families doing ordinary things like going for walks to the park it would allow them hope for the future and begin to reduce some of the uncertainties faced when trying to imagine their life ahead.

In summary the findings presented within the second main theme titled '**This wasn't what we wanted**' offered accounts of the parents' concerns for their child's and family's future as they began to come to terms with the changes they were experiencing as a result of their child dependence on I-LTV. All the parents mentioned uncertainty about what lay ahead and most identified a lack of information and signposting which at times contributed to their frustration and anxiety. Overwhelmingly they described a strong desire to be provided with more accessible and tangible information which gave them hope for the future as they began to come to terms with the changes they were experiencing.

The third main theme titled '**Safer at Home**' will now centre on the parents' anxiety in relation to the child's hospitalisation and concern for their welfare arising from the requirement for I-LTV and the associated risks this dependence brought.

4.1.3 Main Theme 3: 'Safer at Home'

One of the most striking findings to emerge from the interviews was the concept of the child being '**Safer at Home**'. This third main theme focussing on the uncertainty arising from the child's hospitalisation and need for I-LTV emerged as a result of the parents perceiving their child at times would be safer in the home environment despite them being cared for on the critical care or high dependency units, surrounded by qualified and competent staff and innovative and supportive technology.

When the children were critically ill and very much dependent on the intensive care technology and skilled staff, the parents recognised the children were in the best possible place. However, once the children became more stable and were no longer critically ill some parents spoke of a continued fear relating to the safety of their child. At times this was due to the staffing levels which parents perceived to be inadequate for the level of dependency their child required as they stepped down to HDU. At other times it was because of the environment in which they had to leave their child, feeling the children were isolated, exposed and vulnerable and not being cared for by the people who knew them best. As a result of these significant concerns the findings contributing to this main theme of '**Safer at Home**' were grouped under the sub-headings of '**vigilance**' and '**involuntary separation**'.

To understand the perception of the child being '**Safer at Home**' in relation to this apparent dichotomy of being cared for in hospital by clinical experts on hand twenty four hours a day it is important to try and contextualise the fears expressed by some of the parents. Some of these fears related to the potential risks and 'precarious survival' of a child on invasive long-term ventilation and related to the child's unstable health, unpredictable symptoms, and vulnerability of being dependent on technology which put them at increased risk. For one mother there was a '*dawning realisation*' of how this precarious survival would impact on her and the family's life and entailed an existence of vigilance and uncertainty.

Mother (008): you are preserving his life with that tracheostomy and that is what that is there for, and it's not until you know his condition you have to make that realisation that actually at any point, you can't leave him. You can't leave him for 10 minutes because at that time he could... block off and stop breathing.

Additionally, all of these children were to a greater or lesser extent dependent on supportive ventilation. Hence if they became disconnected from the ventilator this could also be potentially life threatening therefore presenting an even higher risk in terms of vulnerability. Because of the potentially high risks and to reduce or prevent any potential harm occurring it is advocated all children on invasive long-term ventilation should have a trained carer present at all times even when medically stable and well enough to be discharged home, which leads on to the first sub-theme finding of '**vigilance**'.

4.1.3.1 Vigilance

Without exception all the parents showed a strong commitment to be present with their child whenever possible, with some being resident in the hospital for many weeks especially when their child was being cared for on intensive care. It was during this time parents spoke of maintaining a vigilance by the child's bedside, wanting to be there all the time, observing their child and the care being provided. This level of vigilance is in accordance with the one to one care provided on the intensive care unit, yet what emerged from the findings of this study contradicted what had been advocated by the healthcare professionals once the child was transferred out of ICU.

Once the child was deemed medically stable and well enough to be stepped down from ICU to HDU the level of nursing care provided was reduced, reflecting the lower level of dependency on the unit. This usually meant the nurses on HDU were caring for between two and four children on each shift and consequently the parents reported there was not always one trained nurse with the child at all times. This appeared to the parents to be in direct contradiction to what they were being taught insomuch as they

were told that once they were home they were to ensure there was always a trained carer with the child at all times.

Although the number of nursing staff working on the HDU are planned to meet the recommended standards for the nurse-to-patient ratio (Paediatric Intensive Care Society, 2010) the reduction in the level of care provided came as a shock to some of the parents as described by one mother when her child was transferred to HDU.

Mother (005): so I said 'what happens now, who stays in here with him?' because I had planned to go home for the first time. And they said 'oh well we come and do his hourly obs (clinical observations)'. 'Hourly!' And I was just like 'oh my God!'

The Paediatric Intensive Care Society standards (2010) recommend that the level of nursing provided on HDU should be one nurse caring for 2 children and should be 1:1 if the child is nursed in a cubicle. However, there were times when parents described staffing was not at the recommended level of support. Sometimes they recalled this was due to staff sickness but they also were aware that the HDU beds were situated on a general paediatric ward where staffing levels were lower and the nurse to patient ratio calculated on a 1:4 basis. Consequently this meant the nurses on HDU were usually required to look after more than one patient per shift and inevitably there were times when children were left on their own without direct observation. As the parents were made aware of the importance of the child always having a trained carer available at all times this became one of the areas causing significant stress and anxiety particularly when they were unable to stay with their child at all times. In addition, the children were sometimes nursed in a cubicle away from the open ward area and not in immediate sight of the nursing staff. Although they all had monitors attached to alert staff when oxygen saturation levels were dropping, there were times when parents felt their child did not receive the level of attention they required especially when the unit was busy and the nurses were caring for other patients. One mother shared her concerns about the level of support and supervision her child received whilst on HDU

and described how anxious she felt about the uncertainty of whether her child would be safely cared for when she wasn't able to be there.

Mother (001): I think we were there most of the time, but I used to really worry about the mornings before we got there. Because, almost every morning that I got in, he either was disconnected or he was crying but obviously no one could hear him... It was again, part of the reason for getting him home I felt like even without carers he was safer here (at home).

Moreover when the parents observed other children being cared for without their parents being present it caused significant anxiety as they recalled having to shout for the nurse to respond to the child's needs which naturally heightened their concerns for their own child's safety and well-being when they were not present.

Mother (001): ...there were times when I had to shout for someone to come and deal with another child because the mother wasn't there. And vice versa. And actually it's not the job of other parents to shout and that made me nervous because I felt like if I'm having to shout for them to come and deal with another child, when we're not there, what if nobody is here to shout for my child when he needs it? So I didn't feel very safe.

This demonstrates not only were the parents anxious and concerned about the needs of their own children but became concerned for the safety and well-being of other children too. This raised the concept of parents becoming hyper-vigilant and taking on new roles to cope with the uncertainties they faced when caring for their child. In this study parents were understandably hyper-vigilant as they were trying to prevent catastrophic outcomes recognising the children were at risk of death if there was prolonged airway occlusion or sustained loss of ventilatory support.

While some parents alerted staff to the needs of children who were not their own, others were described as taking this a step further. One participant described how they observed another parent silence equipment alarms and replace a ventilation circuit that had become unattached on a child who was not their own. Parents described this as taking on a '*nursing role*' and '*overstepping the boundaries*' of providing care for children other than their own. However, although not condoned, it was recognised that when parents became very experienced in caring for their child, and were familiar with the medical equipment they often were seen to help the busy ward staff by assisting them to silence alarms and reposition equipment. Parents believed this situation occurred not just because of the competency and hyper-vigilance of other parents but because they perceived the staffing levels on the unit were inadequate for the number of children being cared for. For this reason the mother spoke of constantly worrying about her child's safety when she wasn't there.

Mother (007): That won't ever leave me that won't. You know I think it's a whole trust thing that even now that's why we're... when [child] was there that's why you're always thinking is anyone going in? I don't want anyone going in to my son's room.

It was not always the safety of the child on reduced care levels of HDU causing parents to worry as they also raised concerns about the safety of their child on ICU. As previously described for some the need for vigilance was often based on fear and the potential risk that not having someone with their child at all times would prevent them from coming to harm. However, one parent spoke of her anxiety about leaving her child in the care of a particular nurse on the ICU unit who she felt was not acting in the best interest of her child. Although caring for the child on a one-to-one basis the mother described a situation leading to feelings of mistrust which undoubtedly had an impact on the ongoing relationship with the member of staff. The mother described how she felt unable to leave her child as the nurse was trying to wean her child off ventilatory support which she felt was too soon, although it was emphasised to the

mother it was so they could cuddle their baby without being attached to the equipment.

Mother (003): I wasn't bothered about having a cuddle... We hadn't had many cuddles at that point but I was more interested in her getting better... I would love to cuddle her 24-seven, but at the time I just wanted her to get better. And this one particular nurse kept trying her off (the ventilator). And she must've taken her off about 10 times and [child] was getting more distressed and distressed and I wanted to put her back but I didn't have it in me to say 'No' she just needs to be... and I was just distraught that night... I just had no trust in her. I could just not wait until she got off that shift.

This situation caused the mother considerable anxiety and distress, so much so she felt unable to leave the unit as she believed her child would be at risk if she wasn't there to observe the nurse and watch over her care. Although she wanted take control of the situation the parent felt unable to challenge the authority of the nurse. This finding provided an example of how the parental role changed from nurturer and comforter to protector as the mother described being prepared to relinquish the physical contact with her child in the hope it would speed her recovery and prevent her from harm.

In contrast, there were other times when the parent revealed feelings of trust and confidence in the nursing staff and their ability to care safely for her child. This occurred once her child had been moved to another unit where the mother felt immediately happier and more relaxed with the care and support provided and commented on how this meant she could leave her child overnight without the worry and distress she had experienced previously.

Mother (003): and they were just lovely, I felt at ease. I didn't even feel that I needed to stay there that night or stay a long time with her there. I knew I felt trust in them their straightaway. I mean I feel like (staff at Hospital) are so lovely. Amazing. Yes there are some nurses that aren't

my favourites but actually even though they're not my favourite I know they care for [child]... so actually I feel like they are my little family in the day when I'm there. So they are really supportive...

This demonstrates not only the importance of a positive and trusting parent-nurse relationship but reveals the benefits of nurses working in partnership with parents to support and build confidence in their abilities thereby creating a sense of security early in the admission.

Other parents described situations when they also became anxious about leaving their child even though their child had started to become more stable and less dependent on the intensive care they once required. One father felt staff believed his child was 'too well' to warrant one-to-one care yet this directly conflicted with the caring strategy the families had been directed to adopt to ensure their child's ongoing safety .

Father (001): because he was deemed too well enough. He was the well-est of the babies.

The shock and fear of realising their child would no longer be receiving one-to-one care on HDU caused one family to change their routine to accommodate and support the reduced staffing levels taking the conscious decision to be with their child more so that he was not left on his own despite having multiple other commitments with other older siblings at home to care for:

Mother (005): but knowing that someone was at the bottom of his bed 24 seven, so then to go to HDU, it was a massive shock. It took a while to settle in and I think that's probably why we stepped up a bit more thinking right we need to be here we need to... you know, he is our baby and we don't want to leave him and stuff.

When the mother was asked what she was worried about she replied 'I don't know... just leaving him I think' which supports the concept of vigilance and the fear of leaving their child alone which was something all of the families spoke of. It also relates to the

fact they hated their child being on their own without the love and care they could provide and raises the notion of the involuntary separation all of these families experienced due to the prolonged admissions these children required.

4.1.3.2 Involuntary Separation

Closely related to the concept of vigilance and directly associated with the parents wanting to be with their child at all times, the subject of involuntary separation emerged as one of the notable findings and became the second sub-heading relating to '**Safer at Home**'.

The involuntary separation of leaving their child in hospital was acknowledged as one of the most painful and distressing times for parents and induced feelings of despair, grief and desperation. Yet there were also examples of involuntary separation within the hospital setting. As already highlighted, one very pertinent example of involuntary separation related to the parents' exclusion from the intensive care ward rounds (in section 4.1.1.2 under the sub-heading of '**Mixed messages**'). Although the separation may have been considered by the healthcare professionals to be for a relatively short period it occurred at one of the times when parents most wanted to be with their child as decisions were being made with regard to care and treatment. Furthermore it was not a separation voluntarily made by the parent's and resulted in them feeling excluded from their child's care and caused feelings of distress, animosity and annoyance. Furthermore it also impacted directly on the time they were able to spend with their child:

Mother (003): You weren't allowed to be there, so you would then get information second-hand... you didn't always get it and actually you couldn't put your opinion across. So when you are travelling so far you didn't know what time the ward round was on so you would travel down and get there at the ward round and you've lost two hours every day.

Notwithstanding the involuntary separation that occurred due to the wishes of the clinicians, the parents also spoke of the difficult choices they had to make in respect of trying to maintain a balance between staying with their child in hospital and the needs of the wider family. Without exception the parents spoke of how difficult it was for them to leave their child alone in hospital and whilst some of them in the initial stages of the admission stayed at the hospital the entire time, as the weeks progressed it became almost impossible for the parents to ensure one of them was always with their child, due to other commitments such as having to return to work and needing to be at home for their other children.

Parents with other children found themselves having to divide their time, attention and loyalties between staying with their sick child in hospital and also trying to maintain as normal a life as possible at home for the siblings. This caused significant distress to the parents with one mother becoming very emotional when she described how hard it was to leave her child in the hospital and go home to look after her other children, despite the interview taking place many months after her child had been discharged home.

Mother (007): I just get so upset when I think about that. And they know on the ward that I was so upset with it all because I was just so like 'God' I can't believe my little boy is on his own.

This anguish was echoed by another mother when she described leaving her child at night to go home to look after her other child. She defined it as being the '*hardest decision*' she faced having to divide her loyalties between providing the parental care for her child in hospital with trying to maintain some sense of normality for her other child at home.

Mother (008): It was the worst possible situation, nobody wants to leave their child, but in that respect, we knew that I had to make a decision that either [sibling] went to somebody else, which wasn't

acceptable and fair on her, or I split myself and that is exactly what I did.

Parents also recognised the situation became even more difficult when the child's health improved and they no longer medically required to stay in hospital yet had to remain as the necessary support was not available due to the home care package and equipment not being ready. A mother spoke powerfully of how she desperately wanted her child to be at home with the family yet accepted she couldn't take him home due to the lack of resources needed to safely care for her child. She spoke of the stress this caused her, whilst recognising it was very different to the stress she felt when her child was critically ill and stated she felt that she was the 'worst parent ever' having to leave her child in hospital when he didn't need to be there.

Mother (001): It's a very different kind of stress when they get to be medically stable, and you feel that you're leaving your child there...every night and you feel like the worst parent ever... Even though you know you've got no choice because you not got the equipment, you're not in this position to take him home. And its soul destroying...

Once their child was considered well enough to be at home the involuntary separation and the distress and upheaval it caused provoked some families to take their child home without all the resources they required being in place. For others the uncertainty of not knowing whether they would be able to cope without the additional support prevented them from taking their child home and caused further anxiety and distress. One mother again described leaving her child in hospital whilst knowing he could have been at home as one of the most difficult experiences for her, but because of the uncertainty of not knowing whether they could cope without the additional support of the carers provided as part of the homecare package they decided they had to stay. Furthermore they also had some doubt about whether they would be able to return to the hospital if they found they were unable to manage:

Mother (005): I think that was the hardest part. Knowing that we could go, knowing that he was ready, but we didn't have the care package. And I think we had talked about going and thinking did we go and just see how we get on and half of us was like but if it doesn't work we can't really come back, so I think that's why we stayed.

Together the descriptions of these families define how difficult it was for them to leave their child in the hospital especially when they believed they no longer needed to be there. However, due to the uncertainty of how they would cope without the support of a home care package, they decided the transition to home would prove to be extremely difficult providing care twenty four hours a day. Therefore most of them took the decision to stay in hospital until the home care support was in place and became another feature of the parents trying to ensure they protected their child from harm.

Another aspect of concern with respect to involuntary separation was with regard to the safety and security on some of the units. Whilst on the neonatal and intensive care units the parents spoke of a high level of security, once the child was on the high dependency unit the level of security was perceived to be reduced and for some caused a great deal of anxiety. For one mother this was an aspect of her experience that featured significantly in her recollections.

Mother (007): So that was one thing that was like a big shock to my system if I'm being totally honest, from neonatal because there... it's full-blown security, you know the time and what time the visiting's are. You've got the buzzer system and it is really, really strict. And I think that's a good thing.

The mother also described that even though the entrance to the high dependency unit operated on a buzzer system, there were times when people were allowed to enter without being challenged. This caused her and her husband great distress as they were concerned for the safety of all the children and although they themselves tried to

stop other visitors from entering if they did not recognise them they described on at least two occasions they were verbally abused by other families trying to enter the unit.

Furthermore, not only were there concerns with regard to who was allowed to enter the unit without being challenged, families also raised concerns about the conduct of other parents on the unit. This sometimes related to the way the parents spoke to the staff either with a lack of respect or with overfamiliarity but also with regard to the role some of the parents took on whilst they were staying with their child. Some described parents providing aspects of clinical care for children that were not their own, whilst others were found to be taking photographs of the participant's children without their permission perhaps not recognising the significance in terms of confidentiality and believing it would be appreciated by the parents and further demonstrated the distress caused by involuntary separation.

Overall the findings in this section recount the parents' descriptions concerning to the protection of their child and focuses on the concepts of vigilance and involuntary separation and highlights the emotional, physical and psycho-social stress the parents experience. As Briscoe (2008) describes when invasive long-term ventilation is commenced life goes on with new vigilance with the individuals taking on new clinical roles and identities. Linked to this vigilance and change in health status, the emphasis of the final findings chapter focuses on the changes in the parental roles under the concepts of 'uncertain' and 'extraordinary' parenting and is titled '**Clawing every little bit back**' .

4.1.4 Main Theme 4: 'Clawing every little bit back'

The final theme titled '**Clawing every little bit back**' focuses on one of the most remarkable transitions in the lived experiences of the parents. This change centred on the changing roles and identities of parents as they navigated through journeys lasting many months initially beginning in critical care and culminating for most in the eventual discharge home. In the early stages of the admission experiences were associated with the loss of their parental role particularly when the children were at their sickest. Yet over time, through multiple changes and transitions of uncertainty, the parents moved towards regaining elements of control and began to '*claw back*' their parenting together with taking on new role identities and responsibilities.

A number of descriptions and interpretations are used to illustrate the findings in regard to changes in parental roles and subsequent development of new skills and are gathered under the two sub-headings of '**Uncertain parenting**' and '**Extraordinary parenting**'. First they centre on the initial role ambiguity faced by the parents following their child's admission and then they consider the significant changes in their caregiving roles and the additional responsibilities they accepted in order to safely care for their child at home.

A wealth of literature can be found on the effects on caregivers when loved ones experience a period of critical illness and as Cejer's (2007) review of literature found, parental role alteration is a main cause of severe parental stress. The reasons for the changes to parental role included the disempowering environment of the hospital setting, a lack of knowledge and understanding in regard to their child's condition and the perceived and at times real paternalistic power of the medical profession, all of which resulted in the '**Uncertain parenting**' described in the first section of this chapter.

4.1.4.1 *Uncertain Parenting*

When the children were admitted to intensive care parents initially found they were relieved of many aspects of the parental role due to the critical nature of the child's

condition and the situational transition ensuing from the admission. This resulted in an involuntary adjustment of caring as the role they usually provided was taken on by healthcare professionals. Parents were challenged to redefine their parental role expressing feelings of helplessness and a loss of control and were left in a state of bewilderment and uncertainty:

Mother (001): personally I found difficult, which is again probably through the whole process, where I feel like you have some of your parenting taken away from you. It feels you're not allowed to just be mum, you're not in charge. ...I think that quite often it felt that everything was out of our control.'

Another mother recognised this loss of control as nurses acted as gatekeepers in determining how and when the parents were able to participate in care and what decisions they are allowed to make:

Mother (003): I remember being asked... "How do you like to cover her up?" and I remember saying 'she doesn't like swaddling' and she just did it anyway. And I remember that, I remember thinking... Why have you bloody asked me that if you're not going to listen to what I say?

Feeling unable to challenge the nurse despite recognising the fact they knew their child better having only just transferred to the critical care unit from another hospital, the parents conceded to what they suggested was the superior knowledge of the nurse:

Father (003): We knew exactly.... we'd been with her for four weeks... we knew exactly how... we would put her on her bed, wrap her up and she would be fine. And she would be insistent that we should swaddle her. She said babies like to be swaddled. I said 'don't swaddle her, we don't want her to be swaddled', and in the end we kind of gave away because I think 'she's a nurse, who probably knows...

In support of these findings, decision-making and having or asserting control over situations was an area most of the parents described in detail throughout the interviews. In general the decision-making could be separated into two main areas; that of making major decisions regarding potentially life changing choices relating to their child's clinical care and conversely the more minor decisions the parents felt were their absolute right and duty to make, such as deciding what they wanted their child to wear.

With the major or life-changing situations some parents described complete acceptance of the professional authority and decision-making role taken on by the clinicians. An example of this was described by the parents of one child when talking about the decision for their child to have a tracheostomy. Neither the mother nor father appeared to question the decision made by the clinicians and justified this on the belief that at that time they felt they did not have the skills, knowledge or expertise to decide what was in the best interest of their child. Therefore they believed it was appropriate for the doctors to make the decision at that particular stage.

Mother (006): ...and then all of a sudden you're in an environment where your parental choices... are sometimes... you're not best skilled to make those decisions.

Interviewer: Did you ever think that at that time it was the wrong thing to do or did you question the decision at all?

Mother (006): no, I just think, they knew best

Other parents described deferring to healthcare professionals at times where they were required to make 'big' decisions regarding their child's clinical care. Yet there were times when parents' spoke of differing opinions about what they believed was in the best interest of the child. An example of this was given by a mother discussing the time when the intensive care consultant informed her they had decided it was in the child's best interest to have a tracheostomy. Despite her child being critically ill the

mother was not certain it was right for her child at that time and refused to agree to the procedure and although her wishes were respected by the clinician, it was perceived as being met with disapproval:

Mother (008): and the ICU consultant said 'This is what's best for him this is what we going to do' bang, bang, bang, bang, bang. And something in me just said 'no'. I said to (husband) 'I am not happy with this.' ...and I just... something in me said 'no, I can't let him have that' at that time. And we didn't have it and I think the consultant was rather miffed wasn't she?

Father (008): Oh, undoubtedly.

Although this description of decision-making highlights how the authoritarian role of the clinician still exists it also demonstrates the power and autonomy some parents felt able to assert when faced with making decisions that would have lasting implications for them and their child. However, the mother also went on to refer to 'fighting against' them and 'feeling bullied' in to making decisions:

Mother (008): I mean the first time the discussion of the trache... I said to my husband, I said... I felt... I don't want to say bullied, but we did feel slightly bullied into it, in the March time, because of how the consultant was.

Although there were some parents that clearly felt more comfortable with the paternalistic role of the medical practitioner making the 'big' decisions regarding significant interventions such as surgery, there was still a strong sense of the parents wanting to be involved thereby retaining an element of control whenever possible. What became evident from the interviews was all the parents valued the feeling of being intrinsically involved in the decision-making process and highlighted the importance of being given information regarding plans and the different treatment options so they could make informed decisions. This was clearly identified by one

mother who spoke powerfully about how both her and her husband wanted to have a recognised role in all the decision-making surrounding their child, yet their perception was they were more involved in the major decisions than they were in the day to day decisions they would normally make as parents.

Mother (001): We didn't want to be in control of his surgery, but we did want to be told about it, so we could make a reasonable decision and feel like we had a role to play in making that decision. And sometimes it felt like the big decisions we were involved more in, than the little decisions. And actually that's the wrong way, well that's not the wrong way, as it should be throughout.

To ensure parents were involved in the care and 'minor' decision-making regarding the everyday fundamental choices it was common practice for staff on ICU to create 'routine boards' at the side of the children's beds to establish a sense of involvement and enable participation of the parents when desired and available. However, it became apparent through the parents' descriptions some staff failed to recognise the importance this negotiation played with one mother describing how she looked forward to washing and dressing her child but was often deprived of this important 'normal' parenting role even when her child had been on intensive care for several months. As the family lived many miles away from the hospital and the time they had to spend with her child was limited and precious they had tried to ensure 'routine' care would be left for them to do when they arrived at the hospital. Emotions of anger and frustration were described when arriving on the unit to find the plans had been ignored by the staff on duty:

Mother (002): And one of the things that I knew I could do for her every day was get her washed and dressed. So you know when you've travelled an hour and a half and you sat in that queue (car park) for another half an hour, it was something I was looking forward to doing. But certain people hadn't read her board, or still decided to be oblivious

to that fact after so many months, and I would walk in and she would have been washed and dressed.

Interviewer: and how did that make you feel?

Mother (002): Crap. You know it's another part of my baby that they are taking away from me. It's not natural to ask 'can I hold my baby today, can I get my baby out of her cot?' I knew I could wash and dress her regardless, but to have that taken away as well.

This mother's description highlights how undermined she felt, perceiving that her child was gradually been taken away from her and that she no longer had responsibility for the normal parental decisions she wanted to make. This also raised an important aspect related to decision-making regarding ownership and the observations the parents made with respect to who 'owned' their child. Another mother and father directly referred to the concept of 'ownership' as they spoke of their experiences and recalled openly discussing this with one of the consultant intensivists and how they felt this was not fully understood:

Mother (001): Right the way through, there were times when I just felt like he's not my son. Not... not emotionally but like... everybody had taken...

Father (001): ownership of him

Mother (001): ownership of him. And I did... I mean when he was on CICU, I actually talked to one of the consultants about it. I said you have to understand that these children, not just [child], all these children in here, don't become under your ownership when they're in here. And there were times particularly on CICU when we felt that they didn't understand that.

The same parents later went on to suggest some nurses may have felt the same way with regard to ownership as suggested by the mothers recollections of a conversation with a nurse on ICU:

Mother (001): Like I remember someone saying "just take it that we basically own your life for the next two years." And she was just a bit... It just was very flippant to me. It was like "yeah, we own you. You are going to be here all the time. Accept."

Although this reference of ownership would perhaps have been inadvertent, these seemingly superficial comments had significant impact on parents creating a sense of their child no longer belonging to them and showed how some professionals perceive the prominence of the role of the hospital in the ongoing care of the children. It also showed how the parents possibly had heightened sensitivity to unintentional remarks and actions, particularly during times of stress and uncertainty.

Most parents spoke of how they had limited involvement in caring for their child. Again some offered accounts of how they had relinquished the normal parenting duties and were limited to 'doing cares' which involved wiping the child's eyes with sterile water. However, as the children's condition stabilised and the parents became more adept at caring for their child, they began to regain a sense of control, re-establishing their role as parents. This became even more evident when moved to the high dependency unit where the care began to be normalised. Yet this transition in parental caring duties was something one mother described as being an area of uncertainty in terms of her understanding of what was expected of her and what she could do without being given permission by the nursing staff:

Mother (005): and I said what do I do about his cares? Because obviously we had got used to doing his cares, wiping his eyes and doing his nappy changing... this that and the other. And I said have you got the things, you know the sterilised water... and she just looked at me and said "you just treat him like a baby, just..." But at that point we hadn't been treating him like a baby and so I didn't know what that was, if you know what I mean. And it was like right okay... they said it to

me as if like 'don't you know? Just use baby wipes and you know, wipe his eyes... and we had always kind of waited to be told what to do...

This demonstrated how the parental involvement on ICU differed significantly from that on HDU, yet the parents were expected to know and adapt to the transition with limited preparation or information. However, even when established on HDU parents continued to describe how they felt their parental role was being restricted by the actions of the nurses who perhaps without realising persisted in determining when activities such as bathing and dressing were to take place. This resulted in feelings of resentment not only because the nurses were preventing them from carrying out important parenting tasks but also as they perceived the nurses taking on some of the mothering role:

Mother (001): I'm not the first person he sees in the morning, and I'm not getting to give him a cuddle if he wakes up at night, so actually giving him a bath was really important. And you get in and you'd find he'd been washed, been changed and they'd chosen his clothes for the day, and sometimes I would be like that's not what I actually wanted him to wear today, but I felt like if I changed him I was being awkward (laughs) do you know what I mean?... But it was little things like that that are so important and you feel really upset and it's like oh... I like giving him a wash and it's already been done.

These accounts again illustrated the significance of the parents being involved in caring for their children and how important it was for them for the nursing staff to recognise the emotional and psychological impact of carrying out the 'normal' parental roles. There were other accounts of multiple barriers inhibiting parents from fully participating in their child's care. These included the disempowering culture and environments of the ICU and HDU settings, together with the fact the parents were not always able to be present with their child due to the prolonged length of hospitalisation. Often the day to day decisions were made by the staff caring for the

child without any involvement or consideration of the parents. While some parent's spoke of nurses stepping back to allow them to participate in their normal parenting duties there was often a need to evolve the care around the routines of the intensive care and HDU environments leading to the parents making social changes to their lives and adjusting their daily routines or relinquishing the care of their child to the staff on the units. This led to feelings of frustration with parents having to fight to reassert their autonomy over the day to day parental roles and responsibilities they perceived had been taken away from them. What became evident through the parental descriptions was that the concept of family-centred care was not always truly embedded as parents described feelings of intrusion into areas of parental care that would normally be theirs. Whilst there seemed to be attempts to involve the parents, the parents described what appeared to be a lack of understanding of how important this was at times of stress and uncertainty, particularly during such prolonged hospital stays.

The perceived lack of family-centred care was at times overwhelming for the parents as they recalled feelings of uncertainty regarding their role especially in the early stages of their child's admission which added to their stress and anxiety. Yet what this study also shows is that due to the children being commenced on long-term ventilation and the consequential changes required in the carers roles, the parents quickly became experts in caring for their technology-dependent child. This exceptional aspect of role transition will now be discussed under the heading of **'Extraordinary parenting'**.

4.1.4.2 Extraordinary parenting

The critical illness of the children and the requirement for invasive long-term ventilation (I-LTV) transformed the parents' 'ordinary' parenting into 'extraordinary' parenting and exemplified the developmental changes required of them as carers.

Parents initially uncertain in their role, through the process of transition, learnt new ways of being in the world and learned to cope with the changes in role identity.

Although parents were living with ongoing uncertainty it also facilitated the opportunity for positive psychological growth and role development. This can be seen as the parents described becoming experts in the care of their technology-dependent children and incorporated their new skills of caring for the tracheostomy and ventilator into their redefined world. The transitions experienced were complex and extended far beyond simply planning for the child's discharge from hospital yet over time, all parents showed how they developed new skills and confidence in caring for their ventilator-dependent child.

With the commencement of I-LTV and because of their child's dependence on technology, parents were expected to take on the new responsibilities to ensure their child's health and incorporate the care of ventilator and tracheostomy in to their lives. Consequently they were required to develop expertise in safely caring for their child so they would be able to look after them at home when medically ready. Training began almost immediately after the child had undergone surgery for the tracheostomy with most parents quickly becoming involved reflecting the significance of the situation they faced. Some parents described taking on the whole challenge of becoming an 'expert carer' with enthusiasm and tackled the training with energy and motivation based on the belief that the sooner they were capable of looking after their technology dependent child the sooner they would be able to take them home:

Father (004): I wanted to learn and obviously the quicker I get trained, the quicker I can bring him home.

Other parents recognised this also provided the opportunity for them to be involved in the caring role which they had been uncertain of and aspects of which had been denied to them for many weeks whilst their child was critically ill:

Mother (005): Because we had gone from doing nothing for him, well everything at home for him for three weeks, to then absolutely nothing... and go weeks and weeks without holding him and all that

kind of stuff so as soon as someone said, 'you can start to do it', we were like great! Let's get stuck in there and let's do it!

In distinct contrast to those that took on the training with an urgency and determination others described being more reluctant to take on the clinical role. This was sometimes because of the fear and the negative emotional aspects connected with performing the tasks, whilst others saw it as a nursing role taking on the duties over and above that of a parent. More than one parent described their role as a nurse as well as a parent:

Mother (007): Do you see it's nursing. Yes it's a nurse. That was really tough I have to say that it's bloody scary.

As the mother recalled how she perceived what she was doing had a clinical responsibility she not only spoke of the fear and apprehension it brought about but how difficult she felt it would be to incorporate it in to her life in addition to the other parental roles occupying her time:

Mother (007): Because you are thinking... oh my word, you have to do everything...

Parental insecurity has been recognised as another consequence of uncertainty and there was clear recognition from the mother that she felt insecure taking on this clinical role. Uncertain she would be able to cope with the increased responsibility she needed the support and reassurance of the nurses and was eventually grateful they had helped her through:

Mother (007): That's what they are there to do and now when I look back at it I am so glad they pushed me to do it all, because I don't think I would have coped if I am being totally honest. I would have just been like 'whoa!' And I came home thinking 'what the hell?'

Yet some parents did not portray the acquisition of multiple roles as problematic. This was illustrated with one father distinguishing with a sense of pride that he would be required to be so much more than a parent having taken on new knowledge and skills:

Father (004): You're the nurse, you're the doctor, everything.

Over a relatively short period of time the parents became competent and gained confidence mastering the new skills required in order to safely care for their child at home. Sometimes the parents became so immersed in learning the new skills and knowledge to care for their child it changed the focus of caring with thoughts turning to technology and related physiology rather than the routine baby care:

Father (006): I couldn't get her right and as I say I'm not medical and she had a heart rate and all the rest of it and I am suctioning the trachea and doing this and I'm checking the tapes... checking the probe and all of that. And after a bit I can't fathom what's up with her, so I said to her nurse 'something's wrong with her', and she said 'have you checked her nappy?' And I said 'ah!'... Because you kind of get into all these medical things and you forget that they're a little kid and you forget all the normal children things.

As the parents adapted and responded to their new lives incorporating the vital care-giving skills, the consequential hyper-vigilance afforded them little personal time. They spoke of how they modified aspects of their daily routines to ensure the safety of their child was paramount and even how at times they had to go from a state of relaxation to quickly responding to the ventilator alarms automatically initiating the emergency life support procedures they had been taught. Even though on many occasions the alarms would be activated due to the ventilator coming disconnected from the tracheostomy tube and would not present an immediate life threatening situation, the parents lived with the ongoing uncertainty that at any stage they would be required to perform life support. This illustrates the intense physical and psychological pressure of living with the constant hyper-vigilance required to ensure their child remained safe as

they all endured the daily threat of the tracheostomy becoming occluded or the ventilator support being disconnected and feeling they were unable to leave their child unsupervised even for a minute. Despite the ongoing fear the parents displayed remarkable resilience and adjustment to the responsibility they held with one father explaining how he had been taught to ventilate his child using an anaesthetic bag should the ventilator fail, but how he felt scared at the thought of this occurring:

Father (006): If the worst comes to the worst I can bag her, and bag her, and bag her... And that's it you get so scared, because... And a lot of the new carers, I think they're told she doesn't breathe on her own and everything and that's quite a scary thing.

These findings again demonstrate the parents' centring their roles on the vigilance and protection of their child and highlights the balance of their roles were heavily influenced by three key factors; the child's condition, the ICU environment and the presence of others. Yet as the children's condition stabilised and they moved away from critical care the parents became more confident and made significant efforts to try and normalise the care and role they were able to provide regaining a sense of control, re-establishing the parental role they had involuntarily relinquished whilst taking on new skills they were initially dependent on the medical and nursing profession for.

The parents also provided examples of how they became more proactive as they became proficient in the clinical skills and were recognised as 'expert carers' and how they valued the fact they were able to take control of providing care without having to ask for permission:

Mother (005): after watching him having suction done for so long it was nice for us to actually be able to do it ourselves and not have to ask someone.

The links of becoming more proactive and parental autonomy were also very clear with one of the parents recognising the benefits of becoming an expert carer as it enabled them to have more freedom in caring for their child in the way they wanted to despite them being in hospital.

Mother (001): ...it was kind of, get yourself trained up as soon as you can, it gives you freedom.

This freedom in caring was also described by a father when he explained that he didn't want anyone else looking after his child at night and believed that by acquiring the skills and knowledge required to look after his son he was allowed to do so without intervention.

Father (004): All the nurses, when I am there, then they never used to come in the room. If he wakes up I am there to turn him. If there is anything, I will call the nurse myself.

As other parents acquired the new skills and gained mastery in caring for their child they also began to negotiate the level of care with the nursing staff they wanted to provide. Correspondingly when healthcare professionals failed to recognise or accommodate this competence and increased desire for autonomy it became a source of resentment and frustration:

Mother (001): I wanted to say to the nurses, he's well now, can you back off a bit and recognise that I'm here and I'm trache trained. And... we need a bit of space, basically without you coming in and telling us what needs to happen, when.

Having relinquished so many aspects of parenting and spending weeks of watching the professionals care for their child, some went on to explain that to re-assert some level of parental control they would intentionally move the times of when their child was due to have care:

Father (001): well they come in and say 'do you want to do the tapes at 11?' And it's like no, we'll do it, we're here all day, we'll do it in our own time. You know, we'll bath him when we want, we'll dress him when we want, in what we want.

Mother (001): you would end up moving it just because... just to be awkward.

Father (001): just to get a bit of control back.

Mother (001): you do, you feel like so much control has been taken away, that you're like clawing every little bit back that you can get.

Due to the heightened sensitivity and recognition they were often unable to care for their child without intrusion from the staff, feelings of resentment and irritation were also described by the parents even when they recognised the nursing staff were trying to be supportive and encouraging them in their new and extended parental role:

Mother (001): I remember someone coming in and saying 'I was just about to put his feed on' and I said 'oh I've already done it' and she went "Ooo, check you out super mum!" And I was like I'm not being super mum I have just fed my baby and it really annoyed me.

Although there was evidence that some nursing staff allowed the parents to care for their child without intrusion, these powerful descriptions epitomise the unique situation the parents faced remaining in hospital from many weeks despite the child being well enough to be at home.

The importance of the parents developing and maintaining relationships with the staff as they transitioned from dependence to independence was also identified by parents. By being involved in the care and demonstrating they too had professional skills the parent's spoke of being treated as 'partners' by the staff and felt this helped them to feel valued in their role and to cope with the changing role identity. As one mother recognised she became a valued member of the team as she offered to train the nurses in how to use new tracheostomy tapes whilst she was on the intensive care

unit, an offer that was accepted and not only helped her to feel valued and respected but also enabled a mutual trust to develop. By sharing her expertise it helped to reduce her anxiety and strengthen relationships and build rapport with the staff. It also highlighted the fact that the parents became more accomplished than staff at some of the clinical procedures due to the fact they had more experience in carrying out these duties in preparation for them to go home:

Mother (001): The reality is we've changed [child's] tapes probably much more than any of the nurses on [HDU] because they don't do them every day because the parents come in and do them.

In addition to becoming experts in caring for their child the parents described other elements of 'extraordinary' parenting as virtually every aspect of the parent's lives involved an element of uncertainty and often their new and emerging world was complex and overwhelming. The parents spoke about struggling to cope with the day to day pressures of trying to continue with some level of normality and worried about the impact on their family and their relationships with their partners and other children. A number of parents expressed feelings of guilt relating to the time they were able to spend with their sick child in hospital and also for not being able to devote sufficient time to the siblings at home. They spoke of the difficulty sharing their time between the hospital and the home realising there would be an inevitable impact of the family and were particularly aware of the bearing the lengthy admission was having on the siblings. Many spoke of the time it took them to travel to the hospital on a daily basis with some living over 70 miles away from the hospital. Yet they still managed to visit their child every single day of their admission which lasted in one case '576' days. Their already pressured time was also made worse by the wasted time they spent queuing for the car park with one mother calculating she had '*wasted 19 ½ days queuing for the car park in the first year*' of her child's admission. The financial impact of travelling to the hospital was also mentioned by one family which they estimated to

be around £30,000 having had to change their car for a more reliable vehicle that would reduce the risk of breaking down on the journeys to and from the hospital:

Father (008): His year and a half (in hospital) has cost about £30,000 and that is just on travel.

Mother (008): That's travel, expenses including car parking.

Father (008): £750 per month in diesel

Mother (008): Yes. And then there is the £70 month car parking fee and then there is the maintenance of the car...

At times the parents also needed to be expert negotiators trying to assert their involvement in their child's care and also fight the bureaucracy of the systems to get the level of funding they felt they required to safely look after their child at home. This was made much worse by the parents being aware of the inconsistencies of the continuing care commissioned in different parts of the country and knowing if you lived in one area the care commissioned would be almost double that of the homecare agreed in another area.

This final section in the findings chapter has focused on the developmental transitions experienced by the parents and initially reviewed the uncertainty and role ambiguity felt as their child became critically ill. This was followed by descriptions of 'extraordinary' parenting that developed as they began to re-establish and expand their caring roles as parents of technology-dependent children. During this time the parents took emotional and psychological journeys fraught with uncertainty and complex decision-making which were affected by the variable communication and support which changed over the months of their child's hospitalisation. The clinical environment of the hospital afforded them little privacy as they had to cope with the emotional uncertainty of their child's future, the added parental responsibility of providing complex clinical care under the gaze of the professionals and the changing role they were required to adopt without negotiation, believing it was their parental duty. As parents finally moved towards their child's discharge their parental roles and identities were re-established and a 'new normal' ensued resulting in the parents

devoting extraordinary care and attention to the needs of their children. Clearly illustrated throughout the study findings are the parents' descriptions of accommodating new ways of being in the world, experiencing personal growth and the development of new skills and identities that culminated in 'extraordinary parenting'.

Father (006): There's a lot of changing, you change as a person and all the rest of it...

4.2 Conclusions

In summary the findings of this study demonstrated the parents' journeys during the time spent in hospital in which their children were commenced on I-LTV. The findings presented in the four main themes focussed on the uncertainties and transitions experienced arising from the child's critical illness and subsequent need for I-LTV. In the first section titled '**Going in to the Unknown**' the parents were confronted by a myriad of uncertainties and multiple complex transfers resulting from their child's critical illness and subsequent dependence of technology. In addition to the anxieties experienced regarding their child's life-threatening illness the parents provided descriptions of how they tried to cope with the unknown outcomes relating to their child's recovery often adopting coping strategies that gave them hope for the future. However, during this emotional and stressful time they spoke of how healthcare professionals added to their uncertainty as a result of inadequate and inconsistent communication. This particularly related to their child's clinical condition and importantly when being excluded from discussions and decision-making, especially during the ward rounds on ICU. One other notable finding relating to the child's illness was the number of transfers experienced between the different hospitals and units as their child's condition altered. Even when the children were making good progress and were able to step down from ICU to HDU the parents described again being confronted by multiple uncertainties. These often related to the staffing levels and changes in routine and personnel on the units and were made more stressful due to the lack of preparation and information given to them prior to transfer.

The second main theme covered under the title of **'This wasn't what we wanted'** referred to the parents' concerns regarding the unknown and uncertain future for their child having been commenced on I-LTV. They expressed fears about the technology especially the tracheostomy and how the child being ventilator-dependent would impact on their lives. They spoke of the loss of normality and the realisation of how they would have to adapt to a new normal, with some parents openly describing how they struggled to accept the changes in both their child's dependence on technology and restrictions imposed on their lives. Parents also highlighted the limited information provided by the hospitals regarding their child's condition and spoke of the need for additional advice and support in what to expect when caring for a child on I-LTV at home. This was highlighted as being something they wanted in the early stages of the admission recognising this would reduce some of their uncertainty and allow them to build hopes for the future in the understanding that their life would assume some sort of normality.

The third main theme titled **'Safer at Home'** illustrated the important findings relating to the sub-themes of 'vigilance' and 'involuntary separation'. These sub-themes highlighted the parents' concerns and anxieties regarding the increased dependence of their technology-dependent child and the constant supervision required to minimise the potential risks associated with I-LTV. They also spoke of the anxiety and related fear of leaving their child alone in the hospital and whilst there was some reassurance when they were being cared for on ICU with 1:1 nursing, once they stepped down to HDU their anxiety increased due to the reduction in staffing levels and the uncertainty of whether their child would be safe without being there to watch over them. No longer receiving the continuous observation advocated by the healthcare professionals, the parents spoke openly of the worry of leaving their child alone in hospital and how this directly contradicted the 'taught vigilance' they had been trained to deliver to ensure their child's safety. However, due to the prolonged hospital stay most of the parents were unable to stay with their child at all times as they had other children at home and additional family commitments. This resulting 'involuntary

separation' became almost unbearable for some parents especially when their child was well enough to be discharged home and resulted in some describing feeling '*like the worst parent ever*' perceiving they were letting their children down.

The final main theme titled '**Clawing every little bit back**' the parents provided illustrations of how their child's critical illness and subsequent need for I-LTV initially left them feeling as though they had lost elements of their parental control and responsibilities with some identifying they felt as though they had some of the '*parenting taken away*'. Not only did the need for I-LTV require to them change their hopes and dreams for the future for them and their child, it also resulted in a change to their parental roles. Initially this resulted in a period of 'uncertain parenting' as they coped with the uncertainties of the intensive care environment and need to relinquish care of their child to the new and unfamiliar ICU staff but later as their child recovered they began to '*claw back*' some of their parenting and responsibilities. As the parents became more familiar with the technology and environment, developing relationships with the clinical staff, they spoke of regaining some of the lost elements of parental control. Additionally with the acquisition of new clinical skills which were essential for caring for their child they became more confident and less dependent on the clinical staff which over time developed in to the parents becoming 'expert carers'. This culminated in a transition towards 'extraordinary parenting' as the parents described negotiating their roles whilst preparing to safely care for their technology-dependent child at home. During this time their recollections demonstrated how they had begun to adapt to the new requirements and responsibilities of caring for a child on I-LTV whilst still trying to cope with the uncertainties of what their new and evolving life would involve, recognising not only had their child changed but they would also change as a result.

In conclusion the findings and themes presented from these insightful and powerful parental descriptions tell of complex and emotional journeys encountered over their child's prolonged hospital admission. Emerging from these rich and detailed accounts are what appear to be two over-arching concepts of 'transitions' and 'uncertainty'

underpinning the parents' journeys. The transitions related not only to the child's illness, hospital admission and multiple transfers encountered but also to the changes in the parental roles and their essential acquisition of new skills. In addition, and often as a direct result of the transitions, uncertainties permeated almost every aspect of the parents' time spent with their child in hospital. As a consequence the overall culmination of the findings resulted in the title of the chapter being 'Transitions of Uncertainty' as summarised in Figure 1.

Due to their significance and in keeping with the principles of hermeneutic phenomenology further exploration of these two over-arching concepts was undertaken by performing a post-analysis review of the literature associated with 'transitions' and 'uncertainty'. By returning to the literature it would provide opportunity to gain deeper understanding of the parents' experiences and would establish if the concepts of 'transition' and 'uncertainty' were unique to this study or had been previously been identified in existing theory related to the experiences of parents caring for a child on I-LTV. In establishing the relevance of the concepts in relation to the findings the next and final chapter of this thesis aims to discuss the parents' 'lived experiences' of their time in hospital caring for their ventilator-dependent child and focuses on where these findings present a new contribution to existing knowledge.

5 Discussion Chapter

5.1 Introduction

The previous chapter presented the findings of this study exploring the complex world of a small group of parents caring for their ventilator-dependent child in hospital. Using interpretive phenomenology based on the principles of Heidegger's (1962) philosophy, the research explored the parents' 'lived experiences', from the child's admission to hospital to the eventual discharge home. Focused on gaining a deeper understanding of first-hand experiences (Flood 2010), the aim of this hermeneutic inquiry was to enter the 'lifeworld' of the parents and interpret the meaning or 'essence' they gave to their experiences. Their 'lived experience' of coping with critical illness and learning to care for their technology-dependent child provided a wealth of data and revealed what appeared to be two overarching concepts of 'transitions' and 'uncertainty'.

This final chapter critically discusses the findings of study and focuses on these two overarching concepts as they emerged as the predominant characteristics of the parents' lived experiences. Due to their significance and in keeping with Gadamer's (1976) principles of hermeneutic phenomenology further exploration of the literature related to the concepts of 'transitions' and 'uncertainty' was undertaken. Two predominant theoretical frameworks were identified from the literature, these being Mishel's Uncertainty in Illness Theory (Mishel 1998) and Meleis' Transitions Theory (Meleis *et al.* 2000). Both were found to contain important theoretical perspectives and shared some resonance with this study's findings. However, based on Gadamerian principles of using new and pre-existing knowledge to analyse and interpret the data, a number of important findings relating to the 'uncertainties' and 'transitions' identified within this study were not considered within Meleis's and Mishel's work. As a result a new model based on this study's findings and bringing together aspects of Meleis and Mishel's theories was created. This new model, seen in Figure 4 (in section 5.6), represents a synthesis of the researched and researcher's thoughts and interpretations in what Gadamer (1976) considers as a 'Fusion of Horizons'. It provides a new and

alternative framework for healthcare professionals to consider and reflect upon the parental and wider family needs when caring for children commenced on I-LTV and as required from doctoral research presents an original contribution to existing knowledge.

Initially this chapter begins by identifying the limitations of the study prior to critically discussing the findings and concludes by discussing the clinical implications of the study and makes recommendations for practice, education and research in line with the intentions of completing a professional doctoral study.

5.2 Study Limitations

Many of the limitations of this study have previously been identified within the methodology chapter, such as the use of conjoint interviews with the parents. As such, all the interviews were conducted with both parents present and may have yielded different results had the parents been interviewed separately (Stewart & Mishel 2000). A further limitation was the interviews all involved parents with children already at home or currently in the process of being discharged and didn't include any parents whose child, due to the critical nature of their illness, did not survive. Unfortunately this is a recognised outcome for some families and despite the medical technology and expertise of the clinical staff, there are some children who fail to respond to the treatment and subsequently die in hospital. As it was acknowledged this would potentially be very distressing for parents to discuss their experiences without having the positive outcome of their child being discharged home, the decision was taken at the outset not to invite the parents of children who had died to participate in the study. Although their views and experiences would be as valid as the parents with children who had survived it was recognised it would add another dimension to the interviews and would have an impact on the findings.

Another limitation was the study involved the participants' experiences of a small number of hospitals and therefore only reflects those individual settings, which may not be reflected in other units. Additionally all the parents had met me before in my

clinical role which may have contributed to bias in their descriptions (Baird *et al.* 2015). Also as previously highlighted, my personal experience of caring for children on I-LTV may have influenced the interpretation of the data although through the phenomenological process of reduction I have attempted to remain transparent with regard to my fore-knowledge and understanding (Heinonen 2015a). However, as Heidegger (1962) recognised the influence of the researcher on the research process is integral to the underpinning philosophy of hermeneutic phenomenology and therefore it can be argued this was in keeping with the methodological approach chosen.

Furthermore, rather than aiming to produce generalizable findings or cause and effect relationships (Rodriguez & King 2009) the aims of this research study was to enable a deeper understanding of the 'lived experience' of a small group of parents. Consistent with the philosophical principles of phenomenology the findings from this study are unique to the individual participants. Yet many of the experiences have been supported by other research studies and therefore add to the existing and emerging evidence regarding the experiences of parents caring for critically ill children. Thus some of the learning from them may be transferable (Polit & Beck 2004). However, the findings are only the perspective of the parents and may not have been an accurate account of what actually happened. Moreover the transcripts were not returned to the parents for validation as the theoretical stance adopted was that member-checking is incompatible with phenomenology (Webb 2003). Consequently there was no edict to prove or generalise findings as it was not the intention of the study to reveal accuracies, only the recollection of events and experiences of the participants in accordance with phenomenological research.

As Lavery (2003) suggests, hermeneutic phenomenology is a process of co-creation in which the researcher gains deeper understanding and new knowledge through a circle of reading, reflexivity and interpretation. Therefore in keeping with these principles the next section will now consider the literature associated with 'uncertainty' and 'transitions' as the overarching concepts identified from the parents' descriptions and interpretation of the findings.

5.3 Theoretical Links to Uncertainty and Transitions

A post-analysis review of the literature associated with the main findings from this study revealed a wealth of publications linking both 'uncertainty' and 'transitions' with nursing practice. There was also widespread acknowledgement that both concepts play an important construct in relation to the empirical and clinical literature associated with illness and health. Using a contemporaneous approach the review of literature focussed on the related impact of 'uncertainty' and 'transitions' on parents with a critically ill child and also when involving children on I-LTV. The discussion will consider the findings of this study in relation to both concepts and will critically discuss the responses and coping strategies employed by the parents as they adjusted to caring for their hospitalised child. Although it is important to recognise where this study's findings support existing literature, the focus will be on the new contributions to knowledge regarding the parents' experiences whilst caring for their technology-dependent child in hospital.

To begin the discussion a brief overview of the concept of uncertainty and associated literature is presented and is followed by an outline of work associated with concept of transitions in health.

5.3.1 Concept of Uncertainty

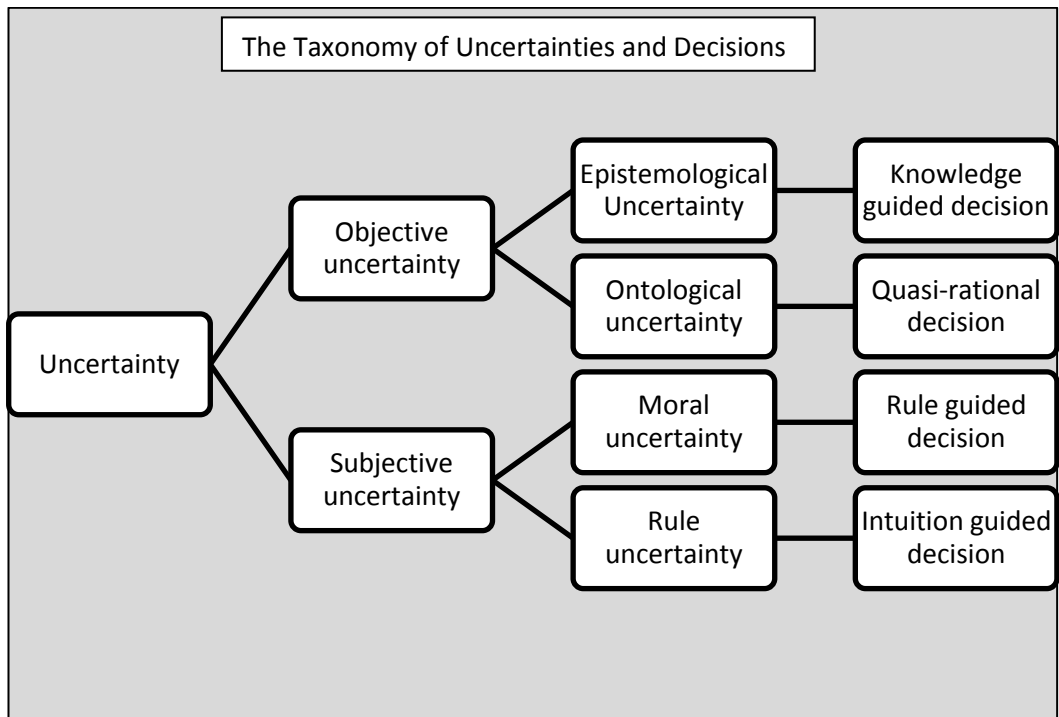
The concept of uncertainty has been recognised throughout human existence (Cohen 1993b) and appears in the theoretical literature in a variety of disciplines (Penrod 2001). Uncertainty has broadly been defined as a situation in which something is not known or where there is a lack of certainty. Generally it applies where there is limited knowledge to an existing state or with regard to the prediction of future events where there is more than one possible outcome. There have been many attempts to quantify uncertainty with acknowledgement that there can be variable degrees of magnitude, intensity and importance (Cohen 1993b). And sources can arise from internal beliefs or external factors that are outside of one's control. Penrod (2001) proposes a definition of uncertainty as:

“a dynamic state in which there is a perception of being unable to assign probabilities for the outcomes that prompts a discomforting, uneasy sensation that may be affected (reduced or escalated) through cognitive, emotive or behavioural reactions, or by the passage of time and changes in the perception of circumstances.” (Penrod 2001 p. 241)

Conditions that contribute to uncertainty are contextual and multidimensional as are the attempts to reduce it. Historically and perhaps still in some primitive societies there have long been attempts to reduce uncertainty, such as through ritual acts, ceremonial rites and sacrifice and some of these can still be recognised in modern-day (Cohen 1993b). However, now the management of uncertainty is predominantly based on cognitive, behavioural and emotive strategies on how to reduce it (Penrod 2001), especially if it is deemed as having negative consequences. This is particularly so within the scientific world when the acquisition of knowledge through experimentation or analysis aims towards obtaining factual certainty. Although it should also be recognised that in some situations uncertainty can be viewed with optimism and can bring hope which results in some people trying to maintain a level of uncertainty. This becomes of high importance and relevance to the parents in this study when the uncertainty was in regard to the existential issues of life and death, also recognised by (Cohen 1993b).

Uncertainty similarly becomes an important concept to consider when there are decisions to make, especially when they have consequences that cannot be predicted. Tannert *et al.* (2007) propose a ‘taxonomy of uncertainty’ (see Figure 2) based on that principle of ethics, suggesting there two fundamental forms of objective and subjective uncertainty which can then be further divided into epistemological and ontological uncertainty. This taxonomy helps to inform how decision-making is reached based on the balance of risks and benefits and is felt to be a useful contribution to how the parents’ may have approached the decisions they had to make with regard to their child’s health and the time spent in hospital.

Figure 2: The taxonomy of uncertainties and decisions as suggested by Tannert *et al.* 2007



5.3.2 Uncertainty related to Health

Studies on uncertainty in health have long been recognised (Davis 1960, McIntosh 1974, Wiener 1975) with these early studies relating to uncertainty in chronic illness such as poliomyelitis, cancer and arthritis. Following this early work a proliferation of studies on uncertainty in illness began with the publication of Mishel's Uncertainty in Illness Scale (MUIS) (Mishel 1981). This was followed by a scale to measure parents' perception of their child's illness using the Parents Perception of Uncertainty Scale (PPUS) (Mishel 1983). Mishel continued to develop her conceptualisation work on uncertainty later publishing her Uncertainty in Illness Theory (Mishel 1988) which addressed the uncertainty occurring when individuals and carers faced ambiguity during the treatment and diagnostic phases of an illness. Within this theoretical work Mishel (1988, p. 225) defined uncertainty in illness as:

"the inability to determine the meaning of illness related events. It is the cognitive state created when the person cannot adequately structure or categorise an event because of the lack of sufficient cues".

Mishel's (1988) original Uncertainty in Illness theory was later reconceptualised to address the continuous uncertainty experienced by those with chronic illness which not only involves the person directly affected but those caring for the individual too (Mishel, 1990). Since these publications much of the literature on uncertainties in illness refers to Mishel's seminal work.

Both the original Uncertainty in Illness Theory (UIT) (Mishel, 1988) and the reconceptualised theory (RUIT) (Mishel, 1990) helps to enable understanding of the response occurring due to changes in health and centred on the three main categories of; antecedents (causes) of uncertainty, appraisal of uncertainty and coping strategies which help to define the adjustment of individuals to acute and chronic illness (Wright *et al.* 2009). Therefore in light of the findings of this study described in chapter 4, I could see how much of the theoretical work of Mishel resonated with the parents' descriptions of uncertainty relating to their child's illness. However, there were a number of limitations recognised in both of Mishel's theoretical models as they failed to address all of the aspects of uncertainty identified in this study. Mishel's theories do not formally identify the parental-role uncertainty when relinquishing aspects of caregiving to nursing staff, a limitation similarly recognised by Turner *et al.* (1990). Nor do they fully consider the uncertainties in the parent-child relationship and family system uncertainty when caring for a child in hospital.

Additionally although Mishel (1988) accepted that uncertainty can be a positive as well as negative concept, her original framework focused mainly on the negative aspects of uncertainty, overlooking the fact that sometimes individuals adopt strategies that focus on maintaining uncertainty to foster hope. While her reconceptualised theory (Mishel 1990) addresses some of the uncertainties parents face when dealing with chronic illness, I recognised that the parents in this study experienced other dimensions of uncertainty relating to their child's unique dependence on technology and precarious survival. Furthermore although the parents' uncertainty was induced by illness of their child, the uncertainties experienced were from a much wider perspective and required broader consideration.

Around the same time as Mishel published her theories relating to uncertainty in acute and chronic health, Selder (1989) presented a 'life transitions' theory which concentrated on the process of resolving uncertainty when faced with a major life change. Although Selder's theory did not address acute or chronic illness specifically her work focused on any sudden disruption of reality which included loss and being faced with life-changing illness such as described by the parents' in this study. According to Selder any disruption to reality leads to uncertainty and a period of transition culminating in a "*restructuring of reality*" (Mishel 1999 p.271) and therefore has high relevance in the context of these parents' experiences. However, there were also aspects of Selder's (1989) theory which did not completely resonate with the findings of this study. Particularly Selder focuses on the management of uncertainty in order to eliminate it, yet there were a number of uncertainties that were important for the parents to maintain as they gave them hope such as the existential uncertainty of whether their child would survive. However, Selder also recognised the permanency of change helps to reduce uncertainty which can then lead to improved coping and adaptation longer term (Macnamara 2014, Mitchell 2009). Hence Selder again recognises important aspects which I suggest these findings show in how the parents' adapted to their child's dependence on I-LTV. Furthermore Selder (1989) recognised uncertainty as a major characteristic in any transition (Mitchell 2009). Thus this reinforced my analysis of the findings in that both transitions and uncertainty were concepts resonating throughout the parents' descriptions and interpreted meanings from this study. However, as I also believed that some transitions occurred without uncertainty playing a major role, such as the developmental transitions spoken of as the parents became 'expert carers' in looking after their technology-dependent child this led me towards considering additional aspects relating to transitions which are referred to later in this chapter.

Although Mishel (1999) recognised there were a number of similarities between her Reconceptualised theory (Mishel 1990) and Selder's Life Transitions theory (Selder 1989) there are also important differences to note. Mishel describes uncertainty as a

gradual process *“beginning as the illness insidiously invades the person’s life”* whereas Selder’s theory centres on a sudden event starting the change process, which is more akin to Mishel’s earlier work on the original uncertainty in illness theory focussing on acute illness and diagnostic uncertainty (Mishel 1988). Additionally in contrast to Selder’s focus of trying to eliminate uncertainty, Mishel’s Reconceptualised Theory (Mishel 1990) addresses the integration of uncertainty in chronic illness into an individual’s life. Thus proposing that living with chronic uncertainty can be accommodated and can be the preferred state when alternative options are considered as having negative outcomes. Again these inferences support the findings described in section 4.1.2 under ‘Uncertain Futures’ as the parents described learning to live with the technology required to keep their child alive.

During the same period as the theoretical work undertaken by Mishel (1988, 1990) and Selder (1989), further conceptual work on the uncertainty experienced by parents facing their child’s illness was being developed by Cohen and colleagues (Cohen & Martinson 1988, Cohen 1993a, 1993b, 1995).

Cohen and her colleague’s work was based on a longitudinal study of the impact of childhood cancer on families (Cohen & Martinson 1988) and focused predominantly on the nature of parental uncertainty. Following the child’s diagnosis, Cohen (1993a) maintained uncertainty was no longer restricted to the single aspect of not knowing what was wrong with their child and spread to other multiple areas of the parent’s life. These multiple dimensions of uncertainty were experienced as existential, etiological, biographical, situational, social and treatment uncertainties which Cohen defined as follows:

- **Existential Uncertainty** related to the threat to the child’s existence or survival and the parents’ awareness of their child’s future being open and undetermined.
- **Etiological Uncertainty** was defined as not knowing the cause or origin of the disease.

- **Biographical uncertainty** referred to the unknown impact the child's illness and diagnosis would have on the personal lives and world of the child, parents and siblings.
- **Social Uncertainty** related to the changes in the once taken-for-granted relationships between the parents and hospitalised child, the impact on the parents' spousal relationships and effect on the siblings.
- **Situational (or environmental) Uncertainty** referred to the parents being confronted by an unfamiliar medical environment in which they were confronted by new rules and regulations which determined what they could or couldn't do.
- **Treatment Uncertainty** related to the difficult decisions the parents had to make concerning the treatment for their child which often had to be made under conditions of urgency.

Furthermore Cohen (1993a) advocated that these dimensions of uncertainty should not be viewed individually but should be considered as a contextual whole in which they interacted and influenced each other.

Whilst Cohen's definitions were limited to diagnostic closure and spread of uncertainty most of these dimensions also seemed to have a high degree of resonance to this study's findings. However, there were additional parental descriptions in chapter 4 that related to other aspects of uncertainty, notably those associated with the temporal and relational features of the parents' experiences. Therefore further consideration is given to these important aspects when discussing the parents' experiences later in 5.4.

In summary a review of the conceptual work on uncertainty helped to confirm that the analysis and interpretation of the findings from this study showed important resonance with the works of Mishel (1988, 1990), Selder (1989) and Cohen (1993a). However, in recognition of where there were additional findings from this study,

further discussion regarding the parents' experiences will be presented in section 5.4. Prior to this a summary on the second overarching concept of transitions is provided.

5.3.3 Concept of Transitions

Derived from the Latin verb *transire*, transition means to go across and has been termed as an event or non-event that results in changed relationships, assumptions, routines and roles (Collins English Dictionary, 2016). Transition is a multiple concept defined by Chick & Meleis (1986 p. 239) as

"a passage from one life phase, condition, or status to another"
"...embracing the elements of process, time span, and perception".

Always being embedded in the context of the situation 'transitions' involve both a process and outcome and can encompass *"complex person-environment interactions"* (Chick & Meleis 1986). According to Schlossberg (1981) transitions may be due to biological, sociological, environmental, historical or other occurrences and may be evident to those involved or may go unnoticed. Schlossberg (1981) also argues that they may also be as a result of a perceived change rather than an actual change with individuals defining the transition accordingly. Meleis *et al.* (2000) agrees with Schlossberg, recognising all transitions are unique to the individual. Some manage transitions smoothly without concern, whereas others struggle to cope with the consequences, due to the complex and disruptive nature of the change (Im 2013, Kralik *et al.* 2006, Leith 1999). And while not all are considered to be difficult many will be multi-faceted and multi-dimensional (Meleis 2010).

Transitions occur when life's circumstances change and result in adaptation, however it should be recognised not all change results in transition (Blum & Sherman 2010). Additionally, according to Kralik *et al.* (2006), transitions occur from disruption which causes a forced or chosen change and results in the construction of a new reality. The outcome being reconstructed identities and adaptation in personal, social, environmental, developmental and situational contexts.

5.3.4 Transitions in Health

Much of the literature concerning transitions in health refers to the work of Meleis and her colleagues (Chick & Meleis 1986, Schumacher & Meleis 1994, Meleis *et al.* 2000). Yet as Kralik *et al.* (2006) identified early work on transitions was based on anthropological 'rites of passage' led by Van Gennep (1960) who identified three distinct phases, these being the pre-liminal phase (rites of separation), liminal phase (rites of transition) and post liminal phase (rites of incorporation). However, although Van Gennep's phases like many of the early frameworks on transitions suggest a linear progression through transitions this study challenges this belief as it can be seen that learning to live with I-LTV involves changes from multiple directions. This concept is supported by Paterson (2001) who argued that transitions involve an ongoing and constantly shifting process particularly when transitions are concerning chronic or long-term illness.

Schumacher and Meleis (1994) identified transition as one of the central concepts of nursing and further confirmation of its importance was later supported by Kralik *et al.* (2006) following their systematic review of healthcare literature when they found widespread use of the term in nursing. Furthermore it was suggested that facilitating transitions for patients and carers should be a focus for the nursing profession as most nurses encounter patients at a time of instability and change (Meleis & Trangenstein, 1994). Al-Yateem & Docherty (2015) likewise acknowledge that active and supportive management of transitions achieves a more effective process and healthier outcomes, while poorly managed transitions add to unnecessary stress and anxiety (Moore *et al.* 2015). Consequently a number of models and theoretical frameworks have been developed to support healthcare professionals to manage transitions more effectively and assist in achieving the best possible outcomes for patients and their families (Broedsgaard & Wagner 2005, Chick & Meleis 1986, Coleman *et al.* 2004, Gibbons *et al.* 2014, Lopez *et al.* 2012, Meleis *et al.* 2000, Melnyk *et al.* 2006, Parkes 1971, Schumacher & Meleis 1994, Selder 1989, Stephens 2005).

Meleis *et al.*'s (2000) collective research presents healthcare professionals with arguably the most frequently referred to theoretical framework aimed at facilitating effective transitions (Ramsay *et al.* 2013). Addressing four main types of transition the framework focusses on change resulting from health-illness, situational, developmental, and organisational perspectives. A brief description of each of the transitions follows:

- **Health-illness transitions** relate to the health and wellbeing of an individual and when they are affected by illness. They consider transitions through the different levels of care and the response of individuals and their carers to the context of the illness (Kralik *et al.* 2006) and as such were of significance in the context of studying the experiences of parents whose children had been commenced on I-LTV.
- **Situational transitions** consider events related to changes in an individual's circumstances such as admission to hospital and can affect the family as well as the patient. They can also include transfers between different hospitals or individual units for example transferring patients between critical care and the ward (Al-Yateem & Docherty 2015, van Manen 2012).
- **Developmental transitions** concern the response of individuals to experiences that occur during the life cycle, such as pregnancy, becoming a parent, aging and death. They also include the developmental changes connected to individual roles such as the parent's acquisition of new knowledge and skills and alterations in role identity (Al-Yateem & Docherty 2015, Ames *et al.* 2011, Blum & Sherman 2010, Hall & Brinchmann 2009, Jackson *et al.* 2003, Kralik *et al.* 2006, and Ludin *et al.* 2011).
- **Organisational transitions** refer to the changes in organisations from a wider social, political, and environmental context and are not primarily focused on the individual experience.

All four categories relate well to the nursing profession although the first three (health-illness, situational and developmental) are particularly relevant to the care of

patients and their relatives (Moore *et al.* 2015) and were therefore felt to be of particular relevance for this study. Whilst organisational transition can include changes in leadership, roles and adoption of new policies and practice they have not been the focus for this study although may have had some relevance in the context of the other three concepts and the impact of transitions the parents experienced.

The framework developed by Meleis *et al.* (2000) also suggests that there are any number of conditions that can influence transitions and recognise these as facilitators and inhibitors. These include personal, social and environmental conditions which can facilitate or constrain both the process and outcome of the transition (Meleis 2010). Meleis *et al.* (2000) also identified the individual components and indicators that characterise healthy transitions from both a process and outcome perspective. These included the process indicators of; 'feeling connected', 'interacting', 'being situated' (location), 'developing confidence' and 'coping', together with the outcome indicators of 'mastery' and 'fluid integrative identities', all of which were considered in the context of this study and were found to be of relevance. The final component of the framework developed by Meleis *et al.* (2000) relates to nursing therapeutics and interventions aimed at promoting and facilitating healthy transitions and restoring dimensions of patient and family health.

Throughout this discussion section reference will be made to health-illness, situational and developmental transitions identified in the model by Meleis *et al.* (2000) as these were considered to be relevant to the findings of this study. The decision to use Meleis *et al.*'s (2000) model is supported in the literature by Al-Yateem & Doherty (2015) who argue that the model provides a comprehensive framework to review health-care transitions. Yet following detailed analysis of the findings in this study I recognised there were also limitations to using Meleis *et al.*'s (2000) theoretical framework in isolation. Notably it failed to address the psycho-social transitions experienced by the parents identified in the findings section titled 'This wasn't what we wanted' (4.1.2). Accordingly Parkes (1971) 'Psycho-social Transitions theory' was also reviewed in light of the findings.

Psycho-social transitions are characterised as life-changing events requiring people to rebuild or modify assumptions they have developed over years (Lowes *et al.* 2005). Furthermore to meet the criteria for a psycho-social transition Parkes (1988) theorised a stressor event must have lasting implications for individuals representing losses and consequences for those affected. Studies exploring the effect of psycho-social transitions in parenthood have mainly focused on bereavement and care of the dying (Parkes 1988, 2010) although the literature recognises other types of loss can constitute psycho-social transformation such as a life-changing illness (Chow 2001, Lowes *et al.* 2005, Messias *et al.* 1995, Shemesh 2008) and childhood disabilities (Burden 1991). Lowes *et al.* (2005) described the diagnosis of childhood diabetes as representative of life-changing for parents. Similarly Shemesh's (2008) study of children undergoing liver transplant, established the parents underwent significant psycho-social change and found the future was called into question. Therefore in accordance with previous literature, I strongly argue that the commencement of I-LTV was a major life-changing event for the parents with long-term consequences and met the criteria of a psychosocial transition suggested by Parkes (1988).

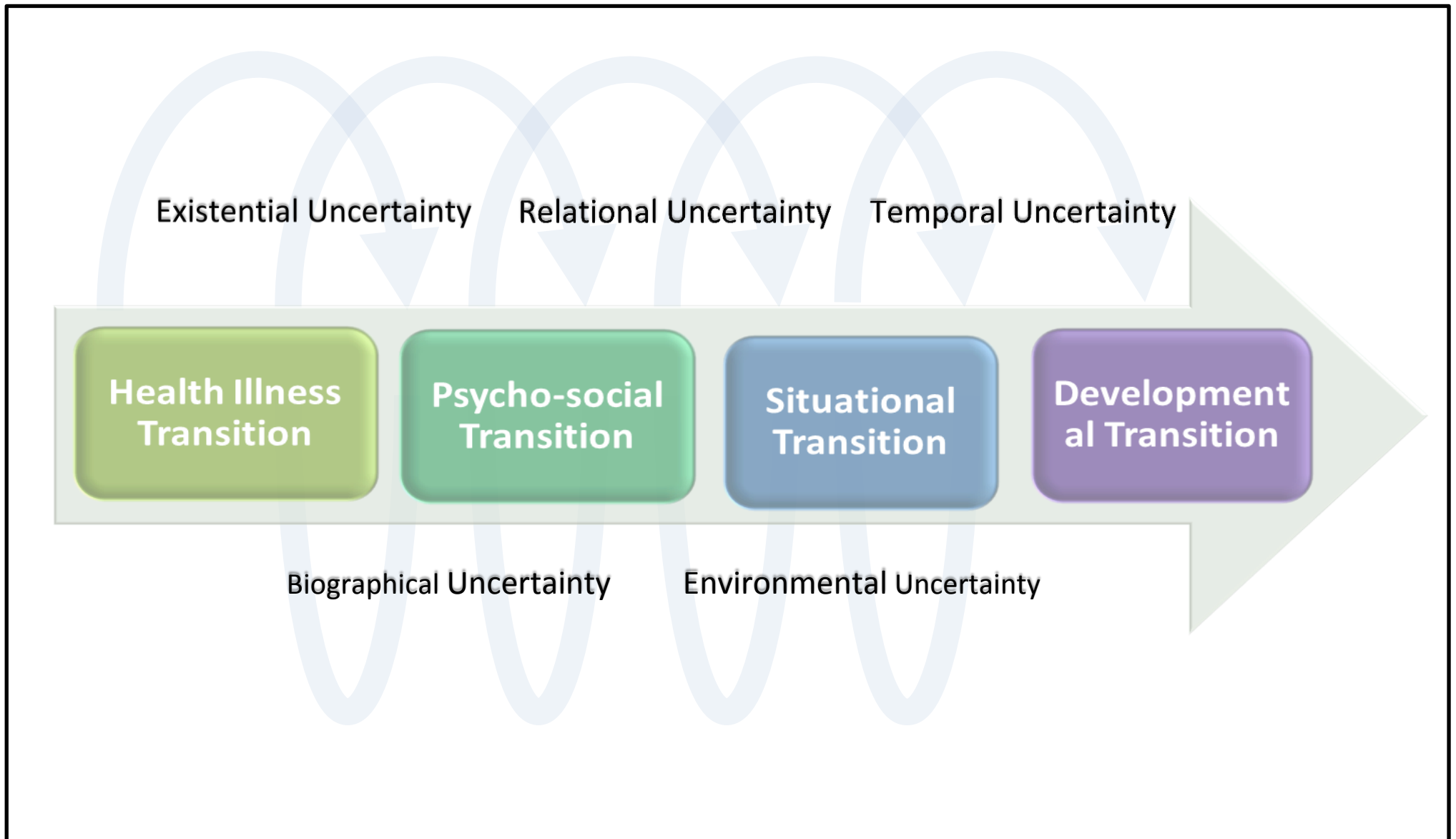
Furthermore the concept of uncertainty did not feature specifically in Meleis *et al.*'s (2000) theory, although uncertainty was recognised as a factor in transitions by Selder (1989). Consequently, as previously described, it became important for me to consider uncertainty alongside transitions due to its prominence in the parents' experiences. Finally, as Ramsay *et al.* (2013) argued, another limitation of Meleis *et al.*'s (2000) transitions theory was that it neglected aspects of relationality and the complex-interactions with multiple-stakeholders. However, I would argue that to some extent this aspect is addressed under the 'transition conditions' and 'patterns of response' as they can be interpreted as referring to the interactions between healthcare professionals, patients and their families.

Having briefly considered the theoretical concepts of transitions the main findings of this study will now be discussed in relation to both concepts of 'transitions' and 'uncertainty'. Emphasis will be placed on the strong links between the theories and

although the concepts are considered separately for the purpose of discussion in reality they formed and interwoven unity within the lifeworld of the parents as depicted in Figure 3.

First the main findings and interpreted meanings associated with concept of uncertainty will be discussed. This will then be followed by a discussion on the findings in relation to the transitions experienced by the parents in respect to their child's ill-health and need for I-LTV.

Figure 3: Diagram to show the interwoven links between the theoretical concepts of 'transitions' and 'uncertainties'



5.4 Parental Experiences of Uncertainty

Uncertainty has been acknowledged as one of the most significant and recognised sources of stress and psychological distress for people affected by serious illness (Cohen 1993a, Dodgson *et al.* 2000, Koocher 1984, Lin *et al.* 2010, Macnamara 2014, Mitchell *et al.* 2003, Santacroce 2003, Stewart & Mishel 2000, Turner *et al.* 1990). Together with the anxiety and psychological suffering, uncertainty has been associated with reduced coping mechanisms and a reduction in the quality of life for those affected (Mishel 1983), all of which were identified in the findings of this study. Mishel's (1988, 1990) theoretical conceptualisation of uncertainty helped to bring an understanding of the response and adjustment seen in the descriptions of parents in this study. Based on Mishel's categories of antecedents, appraisal, consequences, coping, management and outcomes of uncertainty; these classifications provided a helpful structure for discussion of the parental experiences and are now considered in the analysis and interpretation of the findings.

5.4.1 Antecedents of Parental Uncertainty

Mishel (1983) referred to antecedents as the factors causing or contributing to uncertainty and can be categorised in numerous ways. In the context of this study multiple antecedents contributed to the parents' uncertainty and following analysis and interpretation of the findings the parental uncertainties were categorised as arising from the five aspects of existential, biographical, environmental, relational and temporal uncertainty some of which aligned to Cohen's (1993a) dimensions in her study of parental experiences.

In the context of this study 'Existential' uncertainty as identified by Adamson (1997), refers to the threat regarding the child's survival and the parents' awareness of their child's future being open and undetermined. Not knowing whether a child will survive has been described as the 'hallmark' of parental uncertainty when a child has a life threatening condition (Stewart & Mishel 2000). Dimensions of existential uncertainty described by the participants in this study were connected to their child's admission to

ICU, diagnosis, life expectancy, treatment including the I-LTV and longer-term outcomes and meant parents had to cope with the realities of caring for a child where the outcomes were less than certain from several perspectives as described in section titled 'Going in to the Unknown' (4.1.1).

As individuals experience particularly high levels of uncertainty when illnesses are sudden and critical having a child admitted to intensive care is known to be one of the major stressors for parents (Needle *et al.* 2009). Like most admissions to ICU they occurred in the face of a medical crisis with the urgency and critical nature of the transition highlighting the existential uncertainty faced by the parents as they were confronted by the possibility their child may not survive. Often the unexpectedness of the admission allowed insufficient time for parents to prepare and adapt to the situation, and resulted in descriptions of a loss of parental control and changes in role leading to further stress, feelings of helplessness and additional uncertainty all of which have been recognised in other research (Moore *et al.* 2015, Stewart & Mishel 2000) and thus support the findings of this study.

While the existential uncertainties experienced by the parents in this study were of significance and highly important, they were not unique and have been described and recognised in almost every context when a child has a life-limiting or critical illness (Stewart & Mishel 2000). Therefore these findings, whilst not new, add to the existing knowledge regarding this important aspect of uncertainty. Furthermore strategies to manage existential uncertainty should be used by clinicians with caution as research and personal experience has shown predicting an outcome in these situations can be difficult and unwise (Wright *et al.* 2009). However, some of the management strategies used by the professionals and the parents themselves and are described in 5.4.5.

In addition to the uncertainty parents experienced as a result of the critical illness there were also many other unknowns relating to the child's admission and subsequent dependence on I-LTV. Some of these, such as the environmental uncertainty and relational uncertainties linked to the child's admission to ICU have

been identified in previous research and are reported in Stewart & Mishel's (2000) review of the literature on parental uncertainty. Therefore as such again they are not unique but nonetheless are important and should be considered by healthcare professionals caring for these children and their families. However, what was more exceptional were the aspects of environmental uncertainty related to the multiple transfers these children were subject to and are considered within the section on situational transitions in 5.5.4. In addition, the antecedents relating to the biographical and temporal uncertainties warrant specific attention as these were identified as more remarkable to this group of parents.

During the interviews as the parents' spoke of the children recovering from critical illness, the existential concerns appeared to fade from predominance, being replaced by concerns for the future as they tried to imagine the impact having a child on I-LTV would have on their lives. Parents spoke of their anxiety about whether their child would '*have a life*' or whether there would be any quality of life for them once they were home. These concerns related to their child's reliance on technology and the associated risks and have been termed by Rempel & Harrison (2007) as the parental responsibility for safeguarding their child's 'precarious survival'. This shift in perception also recognised by Macnamara (2014) was aligned to the appraisal of existential uncertainty diminishing as there became less inherent danger and the reality of taking a ventilator-dependent child home started to be appreciated.

This perceived 'shift' raises an interesting point as to whether one uncertainty prevails over another at any given time. Measurement of parental uncertainty has been the subject of research for a number of years and since Mishel (1981) first published the 'Uncertainty in Illness' scale, researchers have attempted to measure uncertainty in patients and carers across a wide range of conditions (Mishel 1983, Hilton 1994, Macnamara 2014), although none were identified involving parents with a child on I-LTV. While there is no doubt that the measurement of uncertainty in illness has been found to have a role in assessing whether management interventions are of value, I would argue, along with Penrod (2001) & McCormick (2002) that they have important

limitations. As uncertainty is a process that changes over time I would dispute that using a one-off measurement to quantify uncertainty in parents where there are so many triggers is of limited value. Similarly Penrod (2001) agrees and claims measurement scales could be invalid almost straight after they are performed as they only measure a specific point in time. Therefore measuring existential and biographical uncertainty in these complex situations would be extremely difficult due to the multiple interventions involved.

As acknowledged earlier in the thesis, having a child on I-LTV is a major life-changing event, the magnitude of which I have, in part, observed and which has been reflected in other studies (Carnevale *et al.* 2006, Cockett 2012, Manhas & Mitchell 2012, Wang & Barnard 2004). Some of the psycho-social impacts resulting from the child's illness and requirement for I-LTV are considered in the discussion on transitions as they relate particularly to the loss of the parents' 'assumptive' world. However, other perspectives of biographical uncertainty were connected to parents worrying about whether they would have to replicate the hospital environment in the family home and whether their life would return to some sort of normality. These initial anxieties were predominantly due to the parents' lack of knowledge and understanding of what caring for a child on I-LTV involved. However, as time progressed and more information became available, for most these early worries started to resolve as the uncertainty reduced.

Time was an important element for these parents and many of their descriptions referred to the temporal uncertainties faced such as how long their child would need I-LTV or how long they would need to remain in hospital. However, the parents in this study were affected by multiple temporalities such as the rhythm and routines of the hospital and management on the units, the routines of caring for their technology-dependent child and the social routines in which they constructed their lives. Work by Heaton *et al.* (2003, 2005) examined the social and temporal organisation of families caring for a technology dependent child at home, and raised interesting concepts of how the families lives were structured around multiple temporalities. According to

Heaton *et al.* (2003) various concepts of time and rhythms of natural and social life have been identified in the literature including 'circadian rhythms', 'clock time', 'linear and cyclical time' and 'public and private time' to which they added the concept of 'technological' time to characterise the impact the technology had on the child and the families lives (Heaton *et al.* 2005). Importantly their study found the time demands and routines of caring for a technology-dependent child at home had some negative consequences for the child and their family as they limited participation in social life and lacked compatibility with other institutional and social timeframes (Heaton *et al.* 2005). Yet there were additional temporal implications for the parents in this study as they had to contend with the routines and management of the hospital units where they lacked the control of caring for their child in the home situation. Furthermore they had to cope with almost non-existent 'private time' and were devoid of virtually any 'circadian rhythm' whilst on ICU.

Although attempts were made by the parents and nursing staff to establish caring routines for the children, these were not always respected by the clinical team causing parents significant stress, sometimes triggering emotional reactions regarding the perceived 'ownership' of their child. The descriptions seen in section 4.1.4.1 regarding the uncertainty parents faced relating to 'ownership', similarly were recognised by Shields *et al.* (2003a) in their discussion paper titled 'Who owns the child in hospital?' A number of other studies have also examined the issue of ownership when a child is hospitalised (Corlett & Twycross 2006, Darbyshire 2013, Hall & Brinchmann 2009, Hallström & Elander 2005, Jackson *et al.* 2003, Just 2005, O'Haire & Blackford 2005) recognising healthcare professionals often add to the argument by referring to which doctor or nurse the child 'belongs' to with regard to their care. This highlights a need for professionals to reconsider the professional-parent-child relationship and the use of insensitive language which can sometimes lead to conflict (Forbat *et al.* 2015). Furthermore, I determined that none of the literature that I reviewed had previously focussed on the concept of 'ownership' in parents of children hospitalised long-term or in relation to children on I-LTV. Therefore in light of the findings and what appears to

be the dearth of literature in this area it led me to conclude this would be an area suitable for future research particularly as the children had such prolonged hospital stays.

Linked closely to the concept of 'ownership' one of the most significant antecedents of uncertainty and frustration expressed by the parents in this study related to whether they were 'allowed' to stay with their child during the ward round. Reasons for their 'exclusion' were deemed by the parents as clinician preference and therefore appeared to be dependent on which consultant was on duty as described in the findings in section 4.1.1. Not being present on the ward rounds caused parents significant stress despite national guidance recommending that whenever possible parents should have access to their child at all times and should be involved in all decisions regarding their child's care (Paediatric Intensive Care Society (PICS), 2010). Moreover, exclusion has also been found to be a constant reminder the child is critically ill (Mitchell *et al.* 2003) especially when decisions regarding care and treatment are being made by clinicians in the absence of the parents. In addition the parents' reflections regarding the benefits of being present on ICU ward rounds mirrored previous research which identified the vast majority of parents prefer to be present (Aronson *et al.* 2009, Davidson 2013, Grzyb *et al.* 2014). When parents are involved most report improved satisfaction, reduced anxiety and more confidence in the medical team believing they receive more information, greater consistency and improved care of their child (Kuo *et al.* 2012, Shields *et al.* 2006). Furthermore it helps to diminish fears, reduce uncertainty and builds trust in the relationship between the parents and clinical staff (Aldridge 2005). Conversely a lack of these benefits were voiced by the parents and contests that the units in this study were providing care recommended in the national guidance (PICS 2010). Further still the perceived 'exclusion' from the ward rounds also meant the parents could be separated from their child for up to two hours a day. Having unrestricted access is one of the fundamental needs of parents when children are being cared for on PICU (Latour *et al.* 2011, Shudy *et al.* 2006), yet this study shows that these basic needs were not always

met. This caused parents to feel deprived of their parenting role at a time when they were trying to come to terms with the transition in role identity also recognised by Colville *et al.* (2009) and Wigert *et al.* (2014). Parents in this study also described the exclusion led to them feeling they were being ignored and undervalued, feelings which have likewise been identified by Forbat *et al.* (2015), Lee & Lau (2013), Rempel *et al.* (2012), Shudy *et al.* (2006), Studdert *et al.* (2003a) and Wigert *et al.* (2014).

A review of literature found there are multiple reasons for clinicians to exclude parents from ward rounds, including patient confidentiality, a fear it will add to parents' stress, prolongation of the round by parents asking too many questions and parents finding the medical information too technical to understand (Davidson 2013). Despite these concerns Davidson (2013) argues involving parents in ward rounds may in fact reduce the time taken as they have significantly fewer questions when able to hear discussions and plans for care first-hand. This conclusion was born out by some of the parents in this study as they recalled frequently spending time requesting information about their child when they were not allowed to be on the round. Although arguments for parents to be excluded from the ward round can be recognised and to some extent understood, these concerns have not been validated and directly contradict the ethos of family-centred care. Therefore for many reasons this exclusion should be challenged in the light of the findings of this and other studies. Thus exploration of the reasons for exclusion from both the perspective of the parent and healthcare professional is suggested as a further area for potential research.

Finally one of the other exceptional antecedents of uncertainty identified in this study, again concerning temporal uncertainty, refers to the length of time these children spent in hospital. When children are commenced on I-LTV they commonly spend weeks in ICU whilst their condition stabilises before transferring to HDU where they remain for months whilst the homecare package is established (Neupane *et al.* 2015). The recently published Long-term Ventilation Service Specification (NHS England 2015, E07/S/c) states the average length of stay for a child commenced on I-LTV is between 7-9 months and in keeping with these timeframes the length of stay of the children

involved in this study ranged between six months and two years. This prolonged hospitalisation increased family distress with findings throughout chapter 4 showing an impact on family function in both the short and long term as it not only affected the parents' ability to care for their hospitalised child but also had an impact on the wider family too. Parents were torn between staying with their child in hospital and returning home to maintain some sort of normality especially when there were other children at home. Whilst prolonged hospital admissions are not unique to I-LTV what was exceptional was that for much of the time these children were medically stable and would have been at home if the homecare package had been in place. Moreover some of the children were relatively well during the latter part of their admission and did not need to stay in hospital. Yet they remained as in-patients for a further six months which inevitably had a significant impact on the psychological well-being and quality of life for both the child and family, a finding also recognised by Noyes (2000). Notably, it could be argued from the findings of this study that this had a particularly stressful impact on the mothers involved, as it was they who particularly voiced their concerns over this distressing situation. Describing it as the '*hardest decision*' they faced, with another feeling like the '*worst parent ever*' leaving their child alone in hospital, particularly when there was no longer a medical need for their child to be there.

Evidence from the current study's findings gives some insight in to the feelings of stress experienced by the parents knowing that they were leaving their child in hospital whilst in the knowledge their child was well enough to be at home. The research by Noyes (1999a, 2000, 2006) and Noyes *et al.* (1999) also eloquently highlights the distress and frustration experienced by parents of children on I-LTV when they remain in hospital without a medical need to be there. Yet although not explicit within this current study, Lam *et al.* (2006) identified parents are also meeting their own emotional needs by staying with their child in hospital. Therefore it may result in parents considering they are failing in their parental duties to protect and care for their children and feeling they were either neglecting the hospitalised child or the

sibling at home. Consequently the pressure and distress this involuntary separation causes could be significant and may have longer term implications on both family and emotional function and may be a further area to explore.

Having considered some of the antecedents of uncertainty it is apparent that the parents in this study were confronted by multiple uncertainties. These findings are supported by Elias & Murphy (2012), Noyes (2002) and Noyes *et al.* (2014) in their studies of taking complex and technology-dependent children home. Yet as Mishel (1983) recognised it is the way individuals appraise uncertainty that affects how people adapt to these indeterminate situations which will now be considered.

5.4.2 Appraisal of Uncertainty

Adaptation to uncertainty is affected by the way individuals appraise the uncertainty and how they adopt strategies to cope (Mishel 1990, Stewart & Mishel 2000). According to Mishel (1988) uncertainty is a neutral cognitive state and dependent on the way it is appraised determines its meaning. Cohen & Martinson (1988 p. 89) suggest cognitive appraisal is

‘a continuous process in which an encounter is evaluated and categorised in regard to its significance on well-being’.

In this process multiple variables such as the context of the circumstances, previous experience and information-processing abilities determine interpretation of the situation (Turner *et al.* 1990). This can clearly be seen in chapter 4 as the parents continually struggled to make sense of their child’s illness looking for signs and ways to reduce and manage their uncertainty.

Uncertainty can be interpreted as either a threat when harm or dangers are implied or as an opportunity when it supports maintenance of hope (Mishel 1988). Illustrations of the way the parents appraised situations can be seen throughout chapter 4. Generally falling within the two categories of opportunities and threats these findings

consequently support those of Mishel and colleagues (Mishel 1990, Stewart & Mishel 2000) and had an impact on the strategies they adopted to cope.

Dependent on the appraisal of uncertainty individuals adopt different coping strategies that generally either foster uncertainty to maintain or lead to increased hope, or try to reduce uncertainty and reduce the perceived danger (Mishel 1997). Also according to Lazarus & Folkman (1984) individual factors including personality beliefs and values, intellectual capacity, and self-esteem affect the way individuals appraise uncertainty and undoubtedly these had an impact on the way these parents' appraised uncertainty. Yet for many due to the overwhelming stress and context of the situation the consequences of the uncertainty challenged the parents' ability to cope.

5.4.3 Consequences of Uncertainty

For these parents, like other parents with very sick children uncertainty became a reality and was unavoidable (Green *et al.* 2015, Mu & Tomlinson 1997) with parents describing living on a 'rollercoaster' ride of uncertainty an emotional concept also recognised by Foster *et al.* (2013). Furthermore, as Holm *et al.* (2008) argued uncertainty can also have an influence on parental physical and mental health particularly when there is persistent doubt and ambiguity. This was evidenced in this study with parents describing wide ranging psychological and emotional symptoms such as feeling high levels of distress, anxiety, exhaustion, confusion and guilt, comparable to the findings reported by numerous other studies reviewing the emotional and psychological impact on parents when children are admitted to intensive care (Al-Yateem & Docherty 2015, Ames *et al.* 2011, Azouley *et al.* 2000, Colville *et al.* 2009, Darbyshire 1994, Dodgson *et al.* 2000, Durette 2007, Hall 2005, Holden *et al.* 2002, Khalaila 2014, Majdalani *et al.* 2014, Obringer *et al.* 2012, Oxley 2015, Shudy *et al.* 2006, Turner *et al.* 1990). Associated factors relating to the psychological symptoms have been identified as loss of control (McCormick, 2002), unfamiliar environment (Holden *et al.* 2002), separation (Alaradi, 2014) and inadequate information all of which are described in the context of this study and can be seen in the various sections of chapter 4.

As previously suggested it is widely recognised that the consequences of uncertainty are dependent on the appraisal of uncertainty (Stewart & Mishel 2000) and the strategies adopted for coping are aligned to the appraisal of whether it is seen as positive or negative. Evidence from this study suggests parent's used a wide range of coping strategies which are now considered.

5.4.4 Coping with Uncertainty and Adaption

Much of the research on uncertainty in illness focuses on how individuals employ coping strategies aimed at either reducing uncertainty such as evidence seeking behaviours, or foster uncertainty by avoiding activities which could negatively impact on their hope (Stewart & Mishel 2000). Mishel (1997) contends strategies are predominantly based on emotion-focused and problem-focused approaches and argues that individuals adopt problem-focused strategies when the uncertainty is appraised as positive and emotion-focused approaches when there is a perceived danger. However, along with the findings of this study, Penrod (2001) challenges this is always the case and suggests along with cognitive and emotive strategies, behavioural approaches are also employed to manage uncertainty.

Recognised emotional strategies for coping included the parents consciously adopting a one-day-at-a-time approach to living in the present similarly seen by Cohen (1993b) and seeking information and support from healthcare professionals and other families who have been through similar experiences all of which nurses can actively help to manage and develop (Green *et al.* 2015). Notably parents also actively adopted problem-focused approaches as they sought information on the internet and through social media as they tried to access information on what the future may hold for them. Although some spoke of being provided with booklets from the hospital on how to care for a child on I-LTV, parents who offered this information found them of minimal value suggesting alternatives such as DVD's would be more helpful. This is an important consideration for healthcare professionals and one which is highlighted in the recommendations of this study. However, when it came to the behavioural

strategies adopted the main approach assumed by the parents in this study was to instigate vigilant behaviour.

Vigilance as a concept has been previously well recognised as one of the coping strategies frequently adopted by parents when facing uncertainty in illness (Briscoe 2008, Colville *et al.* 2009, Dudley & Carr 2004, Hall 2005, Jackson *et al.* 2003, Lam *et al.* 2006, Lee & Lau 2013, Meakins *et al.* 2015, Shields *et al.* 2003b). The reasons for parents maintaining a constant presence with their children include monitoring their child's condition (Lee & Lau 2013, Lam *et al.* 2006); wanting to protect their child (Dudley & Carr 2004, Snowdon & Gottlieb 1989) and having fears for their safety (Colville *et al.* 2009). All of which are considered appropriate strategies especially when parents' experience the stress and anxiety of having a critically ill child (Meakins *et al.* 2015) and were articulated by the parents in this study. Similarly Lee & Lau (2013) identified parents adopting vigilant behaviour to watch over the nurse when the care provided is not meeting their expectations or there are aspects of care causing concern. Again these concerns were expressed by a parent in this study as seen in section 4.1.4.

Parents have also been found to adopt vigilant behaviours particularly when children are at risk of unpredictable symptoms and their survival is considered precarious (Carnevale *et al.* 2006, Dodgson *et al.* 2000, Lee & Lau 2013, Meakins *et al.* 2015, O'Brien 2001, Rempel & Harrison 2007, Sällfors & Hallberg 2003, Santacroce 2003, Sullivan-Boylai *et al.* 2003) such as in the case of this study. 'Precarious survival' relates to the child's unstable health, unpredictable symptoms, fragility and susceptibility of being dependent on technology which puts them at increased risk (Rempel *et al.* 2012). This behaviour and extended role adaptation has similarly been described by Meakins *et al.* (2015) who recognised some parents adopt positions of hyper-vigilance when there is persistent illness-related uncertainty, particularly when children are known to be vulnerable as in the situation of having a child on I-LTV. Furthermore Santacroce (2003) suggests parents of children with serious illness and life-threatening conditions, such as those seen in this study, are at high risk of developing post-

traumatic stress disorder (PTSD) owing to the hyper-vigilance and the burden of caregiving, both of which can lead to isolation and have significant psycho-social impact. Additionally there is a growing volume of literature linking admission to ICU with parents developing acute stress disorder (Bronner *et al.* 2008, 2010, Corrigan *et al.* 2007, Mowery 2011, Shaw *et al.* 2009, Ward-Begnoche 2007). Although this was not identified in the participants of this study it was recognised that the research was not focused on this as an outcome and therefore a secondary analysis of the data may reveal similar findings. It is also important to recognise ongoing vigilance has been found to have a negative impact on family function as a result of increased family and social disruption (Meakins *et al.* 2015). As the parents in this study tried to balance their life with the needs of the family unit they often felt torn between wanting to be with their sick child and needing to be at home with their partner and other children. This increased stress and potential impact on the family has also been acknowledged by Berube *et al.* (2014) and may have implications for the future as it is considered to have an impact later on in life for the child, parent and family function. As yet the impact of this level of vigilance in children on I-LTV is unknown as are the consequences of whether it persists after the child no longer requires LTV and therefore this is another area well suited to further exploration.

Aside from the findings above one of the most important and unique aspects of this study relates to the fact that in addition to the parents adopting their own strategies to cope with uncertainty, these families were specifically taught by the healthcare professionals to be vigilant. This 'taught' vigilance, also recognised by Meakins *et al.* (2015) in their study of parents caring for children with a hypoplastic left heart, occurred in this study as soon as the child had a tracheostomy. Directly relating to the protection of the child, the parents were trained to recognise subtle clinical changes which could suggest early deterioration in the child's health. They were also taught vital life-saving techniques in caring for their technology-dependent child in the event of an emergency such the tracheostomy become blocked. Importantly they were also taught that the child should never left be alone and should always be fully observed in

case of airway occlusion, accidental decannulation or disconnection from the ventilator. Therefore this vigilant behaviour had a strong functional relevance as identified by Darbyshire's (1993) review of parental participation in hospital. Furthermore the one-to-one care provided on ICU reinforced this message. However, as the child's condition improved and they were transferred to HDU they no longer received the 1:1 care afforded on ICU due to the reduction in staffing based on recommended levels of nurses for the acuity of children on HDU (RCPCH 2014). Consequently the level of observation provided by the nurses on HDU was perceived as being in direct conflict to that previously advocated by the clinical team involved. As a result some parents described being frightened to leave their child and openly expressed anxiety and distress as the 'taught' vigilance they were told they had to adopt was not being upheld.

With further consideration of the findings in this present study and with the understanding that I had regarding the reduced levels of care on HDU, I was aware that this was one of the main sources of parental distress and anxiety. Consequently the loss of one-to-one care and the reduction in monitoring of their child's condition brought about new uncertainties and concerns expressed by most of the parents in this study. However, findings relating to reduced monitoring on HDU are not unique and have been reported by other researchers who have explored parents' perceptions of stepping down from ICU to HDU (Berube *et al.* 2014, Colville *et al.* 2009, Coyle 2001, Keogh 2001, Obas *et al.* 2015). Yet in contrast to most other studies the parents in this study had additional considerations to contend with. Firstly as already mentioned, professionals had taught them the necessity to adopt 'vigilant' behaviour. Secondly their children had excessive lengths of stay in comparison to most children in hospital, meaning that for much of the time the parents were not always able to stay with their child due to their other family commitments at home. Consequently the 'functional importance' as identified by Darbyshire (1994) was unable to be maintained by the parents and the behavioural coping strategy of 'vigilance' was directly contradicted by the care HDU provided. Although the term 'Mixed messages' has been used in chapter

4 to highlight the findings regarding inadequate and contradictory communication I contend that it also effectively captures the uncertainty experienced by the parents in relation to the management of the children on I-LTV when they were transferred to HDU. Therefore recognising this incongruence and understanding the parents' concerns and feelings of insecurity are particularly important for professionals to address especially during preparations for transferring the child from ICU. Furthermore new models of care providing enhanced levels of support and supervision for children on I-LTV are one of the recommendations arising from this study.

Notwithstanding the vigilant behaviour adopted by the parents as one of the coping strategies to reduce uncertainty a number of additional management strategies were recognised in the descriptions of the parents. However, the findings were not exceptional to this study therefore they are summarised briefly in the next section in acknowledgement of their pertinence to management of uncertainty.

5.4.5 Management of Uncertainty

Apart from the management strategies previously identified a number of alternative approaches were described in this study including information management where parents sought facts through questioning and evidence gathering to assist in reducing uncertainty. In addition emotion-focused and problem-focused strategies were adopted including seeking support from other parents who had previous experience of caring for a child on I-LTV and gaining knowledge through education and training. However, as previously argued reduction in uncertainty is only one of a number of responses to management (Brashers 2001). Furthermore as Woodgate & Degner (2002) ascertain, uncertainty is a factor in maintaining hope. Correspondingly rather than trying to eliminate uncertainty the findings show how these parents at times tried to integrate elements of uncertainty into their lives, particularly when their child's existential uncertainty was foremost in their minds. Consequently these findings support the need for professionals to help people to cope with the uncertainty rather than trying to remove it altogether.

Additionally, although quantifying some of the parental uncertainties was not considered at the time of the interviews, on reflection 'measurements' of uncertainty suggested by Stewart & Mishel (2000) as one of the first steps to management may be an area of interest to explore. Although recognised as having clear limitations, used in the right context such as assessing the outcome of intervention, measurement of uncertainty could help healthcare professionals to tailor management strategies to different situations. Therefore it could be argued that one particular aspect of the parents' uncertainty that would benefit from more objective assessment relates to the transfer of children from ICU. As the provision of written and verbal information regarding transfers has been found to be effective in reducing uncertainty (Bouvé *et al.* 1999) I would support a more objective assessment being utilised to assess the impact of such interventions. Although this is important for all transfers it would be particularly relevant in the preparations for stepdown to HDU for this group of parents.

5.4.6 Outcomes of Uncertainty

As Cohen (1995) surmised caring for a child with a life-threatening illness transforms a parent's world to one of living with constant uncertainty even when the child's condition is considered to be under control. Psychological change and adjustment are recognised outcomes of uncertainty Mishel (1988). However, positive changes such as personal growth have been identified particularly when individuals experience prolonged uncertainty (Mishel (1990). Other authors have also identified personal growth as a positive outcome of uncertainty (Gibbons *et al.* 2014, Harkness *et al.* 2013, Madeo *et al.* 2012, Rempel *et al.* 2012, Stewart & Mishel 2000) recognising individuals grow and find new strength and meaning in life as they incorporate the process of coping with the realities of unknown and unpredictable outcomes. Conversely research has also identified negative consequences of persisting uncertainty such as parental anxiety and depression (Madeo *et al.* 2012). While the parents in this study all expressed feelings of anxiety none spoke of feeling depressed at the time of the interviews. In addition although the parents did not specifically identify new meaning

and purpose in life, their descriptions of how they adapted to their new 'life-world' demonstrated adjustment in their parental roles. These transitional elements and related phenomenon arising from the children's critical illness and subsequent need for I-LTV will now be considered in the next section on the parents' experiences of transitions.

5.5 Parental Experiences of Transitions

This section aims to discuss the findings experienced by the parents in this study in relation to the concept of transition and the related literature. The section, structured on Meleis *et al.*'s (2000) framework, will consider the nature of transitions (including types, patterns and properties), facilitators and inhibitors and finally the process and outcomes as experienced by the parents. The final component of the framework, nursing therapeutics, is given consideration throughout the discussions. However, as the aim of the study was to explore the parents' experiences it was not the intention to focus on the nursing interventions. Nevertheless further attention to the role of the nurse will also be considered within the clinical implications arising from this study.

As numerous aspects relating to transitions emerged from the parents' descriptions the discussion will centre on the more exceptional findings of this study. However, reference will also be made to findings that support or challenge existing literature regarding transitions as this will further add to the credibility and trustworthiness of the study.

5.5.1 Nature of Transitions

The parents in this study experienced multiple transitions in a world of complexity and uncertainty, with all experiencing transitions from a health-illness, situational, psycho-social and developmental perspective, triggered by the onset of the child's illness and subsequent need for I-LTV. Transitions were extensive and far reaching and impacted on numerous aspects of their lives supporting the theory that multiple transitions can happen simultaneously (Kralik *et al.* 2006, Schumacher & Meleis 1994). However, each of the four types of transition is considered separately for the purpose of discussion.

As described by Meleis *et al.* (2000) the nature of transitions refers to the types, patterns and properties involved and includes the events and critical points marking the transition. From analysis of the findings the critical points identified in these transitions were the child's admission to ICU, commencement on I-LTV, transfer between hospital units and the step-down to HDU and finally the eventual discharge home. These will now be discussed commencing with the events surrounding the health-illness transition.

5.5.2 Health-Illness Transition

As Bridges (1992) recognised every transition begins with an ending. Accordingly as the children became ill, the parents were required to let go of their familiar world being thrown into a new unaccustomed clinical world of ICU. Due to the critical nature of their conditions all eight children required admission to intensive care and ultimately required invasive long-term ventilation (I-LTV) to facilitate recovery or to stabilise them medically.

Some of the general themes identified in this study relating to health-illness transitions were similar to those found in other studies of parental experiences in critical care such as the emotional impact and distressing nature of the admission to ICU (Al-Yateem & Docherty 2015 Darbyshire 1994, Hall 2005) and the impact on decision-making abilities of the parents (Carnevale *et al.* 2006, Madrigal *et al.* 2012, 2016, Shudy *et al.* 2006). The urgency and critical nature of the transitions highlighted the existential uncertainty faced by the parents as they were confronted by the possibility their child may not survive. This uncertainty discussed previously in section 5.4.1 emphasised the multiple psychological and emotional symptoms described by the parents and reinforces the strong links between the health-illness transition and uncertainties experienced by the parents. In support of this association Brown & Powell-Cope's (1991) study, describing the experiences of family caregivers looking after an individual with Acquired Immune Deficiency Syndrome (AIDS), identified uncertainty as the core category in the transitions experienced. Similarly Selder (1989)

and Golan (1983) also support the inter-relationship between uncertainty and transitions with Golan using a working definition of transition as

“a period of moving from one state of certainty to another with an interval of uncertainty and change in between” (Golan 1983 p.12).

However, unlike Golan I would argue that the findings in this study suggest some of the transitions linked to the child’s illness and need for I-LTV were dynamic and continual and were far from reaching a state of certainty. This argument is discussed further in the section on outcomes of transition in 5.5.7 and will also be considered in the psycho-social transitions experienced by the parents in 5.5.3.

Like most admissions to ICU they occurred in the face of a medical crisis and offered the parents little or no choice in what they felt had to be done to save their child as identified in the findings section 4.1.1. One of the essential roles of parenting, it is well recognised that decision-making becomes distorted when parents experience their child being admitted to hospital even for a relatively short stay (Madrigal *et al.* 2012, Needle *et al.* 2009). In keeping with other studies examining the role of decision-making (Ames *et al.* 2011, Shudy *et al.* 2006), the parents frequently surrendered aspects to the healthcare professionals involved in caring for their child especially when there were major decisions to make such as the need for a tracheostomy, although there were notable exceptions to this. Additionally when parents faced the distressing situation of their child being cared for on ICU, their heightened emotions further impacted on their ability to make decisions and they frequently deferred to the perceived expert knowledge of healthcare professionals as seen in the studies by Carnevale *et al.* (2006) and Shudy *et al.* (2006).

These findings of this study largely support the literature describing concepts of decision-making in ICU and found the role and behaviour of healthcare professionals had a significant impact on parental decision-making as seen by Madrigal *et al.* (2016). Although some parents in the current study perceived that they had a role in significant health-illness decisions such as the choice for a tracheostomy, others

acknowledged their emotional distress, level of knowledge, lack of experience and familiarity with the situation meant their decision-making abilities were compromised. In these situations it was recognised that some parents left the decision-making to the professionals as they believed they would judge what was in the 'best interest' of their child, a concept recognised by Hallström & Elander (2005). Similarly Carnevale *et al.* (2006) agrees maintaining decisions regarding life support for children in critical care is ultimately the responsibility of the clinicians believing parents do not have the experience or sufficient knowledge and should be protected from feeling culpable for making such difficult choices. To some extent I support this argument, as the emotions and difficulties in making decisions in these situations is complex and distressing for parents. However, I would argue that parents should be offered a role in decision-making regarding their child's treatment and care with decisions being based on an informed choice.

This leads to reflection on Tannert *et al.*'s (2007) 'taxonomy of uncertainty' and the findings of the parents' descriptions regarding their involvement in the PICU ward rounds and particularly whether they were provided with sufficient information to make informed decisions regarding their child. As Tannert *et al.* (2007) describe when individuals have insufficient knowledge and information there can be a mismatch between the knowledge required and knowledge available to make rational decisions. Hence when there is objective uncertainty caused by gaps in knowledge it becomes an ethical responsibility for clinicians to address those gaps where possible (Tannert *et al.* 2007). I would further argue that not involving parents in ward rounds where decisions are made regarding their children's health fails to address this mismatch and for a number of reasons this 'exclusion' is unethical and should be challenged. Yet as this study focuses only on the parents' perceptions of their experiences, conclusions regarding the extent of their 'exclusion' from the ward rounds cannot be drawn from the data although personal experience would support these are not isolated findings. However, I would suggest consideration of their perceptions alone makes this of sufficient importance to further explore. This could either be through research or by

discussing the findings in relation to the recommendations of the national guidance regarding parental involvement (PICS 2010).

Similarly, very little in the parents' descriptions suggested they knew much if anything regarding I-LTV prior to the decision for their child to have a tracheostomy. Although sometimes the decision for a tracheostomy may have been taken with the aim for it to be short-term there were potentially other situations in which the intention was always for the child to be discharged on I-LTV. From personal experience which is supported in the literature (Halley 2012) decisions for tracheostomy and I-LTV are often made by clinicians before a discussion on the risks and benefits of long-term ventilation are held with the parents. Therefore in light of these findings and the literature to support discussions regarding I-LTV taking place early on in the child's admission (Neupane *et al.* 2015) I would suggest this could also be an area to consider for further research.

In regard to other aspects of change linked to the health-illness transition one of the most notable findings arising from the child's commencement on I-LTV led to consideration of the psycho-social changes emerging from the parents' descriptions. As they recounted their experiences of their child's life-changing illness they told of their fears and concerns for the future for their child and family and how they recognised they were losing sight of a world they knew and had planned for.

5.5.3 Psycho-social Transitions

Parkes (1971) theorised that life-changing events such as a child being commenced on I-LTV requires parents to undertake major revisions of their 'assumptive' world. Burden (1991) described the 'assumptive' world as one which contains thoughts and ideas of a future hoped and planned for. Hence closely linked to the psycho-social transitions many of the parents in this study spoke of the biographical uncertainty of what lay before them as they became aware of the discrepancy between a 'life that should have been' and a 'life that was' as recognised by Lowes *et al.* (2005). In accordance with Burden (1991) and Lowes *et al.* (2005) the findings described in

section 4.1.2 titled 'This wasn't what we wanted' illustrated some of the psycho-social transitions experienced by the parents as they spoke of the discrepancy between a world they had hoped for compared to the reality of what they faced. Particularly the descriptions in 'Uncertain Futures' revealed parents were required to modify their assumptions about their anticipations of becoming a 'normal' parent, revealing lost hopes and dreams where the thoughts of changing nappies were replaced by the thoughts of changing tracheostomy tubes.

During psycho-social transition Burden (1991) argues that it is entirely normal and expected for parents to pass through a series of emotional stages in the process of adjustment which include experiencing initial shock, realignment of personal values and readjustment of parental roles. The initial shock and emotional responses within the current study were easily identifiable from the parents' descriptions. However, Burden (1991) also recognised a number of sub-stages in the period of initial shock including shock, disbelief, denial, rejection and confusion. Many of these stages have been recognised in other theoretical models of grief and personal loss with arguably the model by Kübler-Ross being the most recognisable (Kessler & Kübler-Ross 2005). As the stage of initial shock usually occurs early in the transition process these sub-stages were not always evident from the parents' descriptions. However, this is not to say that they did not occur but is more likely to be due to the period of time lapsing between the child's admission and the interviews taking place. Nonetheless some of the parents' descriptions showed aspects of denial and initial resistance to the change. This was evident for example when a mother spoke of her reluctance to be introduced to other babies with tracheostomies, not wanting to accept the new reality in which the world of caring for a baby with a tracheostomy was seen to be the norm. In addition another mother initially displayed resistance to her child having a tracheostomy and refused to agree to the procedure, despite her acknowledging this was against the opinion of the medical team. This resistance to change recognised as one of the characteristics of psycho-social transitions emphasised by Parkes (1971), conceivably provides an illustration of the parents progressing through these initial

stages of shock. The same parents, who later agreed for their child to have a tracheostomy, spoke about the major adjustment they were required to make in accepting their child had significantly changed suggesting evidence of one of the transitional properties of awareness as described by Meleis *et al.* (2000).

Although not all the children required I-LTV on a permanent basis it was recognised by two of the families that the tracheostomy and ventilatory support would be required throughout their child's life. Accordingly the parents' awareness of this change indicated that they were cognisant of the permanency of the transition. As Selder (1989) maintained, confronting and acknowledging permanency can help in the transition process. Furthermore acknowledging permanency can help individuals to live with some aspects of certainty in their readjusted lives (Selder 1989). However, it was also recognised from the parents' descriptions that the child's dependence on I-LTV required them to redevelop models of their world which contained situations which some found hard to accept. Professionals therefore need to be conscious of the grieving process brought about by transitions and understand it may take time for parents to come to terms and accept a world different to one they had hoped for (Gibbons *et al.* 2014).

Many of the anxieties expressed by the parents were described in the initial stages of their child's admission and when they were still naïve to the realities of how their life would change. Although some parents continued to vocalise concerns even when they were home, demonstrating the variance in coping and adaptation with the changes to their lives. However, as Burden (1991) recognised the period of initial shock crisis can last for many months, therefore it may have been that some parents were still progressing through these early stages and were yet to achieve a positive resolution at the time of the interview. It is also recognised that sometimes transitions have no endpoint and fail to reach a stage of certainty, as recognised by Paterson (2001) in her 'Shifting Perspectives' model of chronic illness. Therefore in contrast to the definition posed by Golan (1983) of each transition reaching a state of certainty, these findings may conceivably be describing an ongoing transition process rather than representing

progression through to an end stage. Nonetheless Burden (1991) maintained following a positive resolution to transition there will be an acknowledgement of the reality of the situation and readiness on the part of the parents to face the future with whatever it should bring. Accordingly some of the parents' descriptions, for example the mother describing how she equated suctioning the tracheostomy with changing her child's nappy, clearly demonstrated acceptance of her new reconciled world and supports Burden's theory.

Prior to further discussion on the process and outcomes of transition and the related facilitators and inhibitors, two other types of transition, recognised by Meleis *et al.* (2000), are now discussed in light of the findings of this study. First the exceptional elements associated with the situational transitions experienced will be highlighted, followed by discussion on the developmental transitions affecting the parents. This will also lead to identification of some of the patterns of response in which some of the process indicators and outcomes of the transitions will be emphasised.

5.5.4 Situational Transitions

Linked closely to the child's health-illness transition were the situational transitions and related environmental uncertainty faced by the parents as their children were admitted to hospital and transferred between various clinical units. The experiences of parents trying to negotiate an unfamiliar clinical world when a child is diagnosed with a life-threatening, chronic illness are well recognised in the literature with Cohen (1993a) attributing the term 'situational uncertainty' to these experiences. Despite the parents in this study being exposed to unfamiliar clinical environments centred on the technology required to keep the children medically safe, the main findings associated with the situational transitions were the multiple transfers the children experienced as they were moved between hospitals units to ensure they were cared for in the most appropriate clinical environment for management of their conditions.

Analysis and interpretation of parents' experiences suggested these transfers were particularly significant and clearly demonstrated heightened awareness of this type of

transition. Although these transfers are not uncommon and were generally acknowledged by the parents in this study as being necessary, they provoked significant anxiety and distress often exposing the parents to highly-complex and unfamiliar technical environments similarly seen by Ludin *et al.* (2014). Parents reported transfers as '*daunting*' and '*awful*' and used phrases such as '*going in to the unknown*' to signify the stress they experienced, themes consistent with other literature exploring the experiences of parents transferring in similar situations (Chaboyer *et al.* 2005, Coyle 2001, McKinney & Melby 2002, Mitchell & Courtney 2004, and van Manen 2012). Also, as recognised by previous research, parents not only suffered considerable anxiety when transferred between ICU's but experienced 'transfer anxiety' when stepping-down from intensive care to HDU (Berube *et al.* 2014, Bouvé *et al.* 1999, Coyle 2001, Keogh 2001, Leith 1999, McKinney & Melby 2002, Mitchell & Courtney 2005, Obas *et al.* 2015). To some it was the fear of the unknown with the altered surroundings and introduction to different healthcare professionals, while for others it was anxiety brought about by the reduced monitoring of their child as discussed earlier under the section on environmental uncertainty in section 5.4.1.

The findings in this study support the theoretical work of Meleis *et al.* (2000) regarding situational transitions being one of the types of transitions experienced. Yet the more notable findings linked to this transition relate to the associated transition conditions described by Meleis *et al.* and are considered with regard to the facilitators and inhibitors experienced by the parents. Through reflection on the parents' descriptions in section 4.1.1 it became apparent some healthcare professionals afforded little attention to the transfer of the children between units and hospitals. Notwithstanding the reason for the transfers most parents recalled a lack of preparation, communication and information especially when recalling their experiences of transfer from ICU. As supported in the literature the findings of this study suggest the predominant thoughts of the professionals were often in regard to the meaning associated with positive or negative aspects of the child's condition and the need to

transfer them to a unit better equipped to care for their needs rather than considering the effect on the parents (van Manen 2012).

Transfers to HDU were generally planned as the children's conditions stabilised and consequently most parents were aware they were happening and saw the outcome as positive. Yet in accordance with previous research they found the transfer from ICU to HDU to be one of the most stressful experiences they faced and for some caused feelings of distress similar to those experienced at the time of their child's admission (Berube *et al.* 2014, Colville *et al.* 2009, Keogh 2001). As Neupane *et al.* (2015) described, parents of children requiring I-LTV develop significant trust in ICU staff as could be seen in this study. Consequently they need time and information to prepare for transfers such as step-down to HDU. Yet the parents' descriptions demonstrated professionals were sometimes oblivious to their needs and the trauma the transfer brought about. Mitchell *et al.* (2003) suggest planning for transfer to the ward should commence as soon as the patient arrives on intensive care yet the findings from this study suggest this was not usually the case. Conversely the parents' descriptions showed most felt they were not sufficiently prepared for transfers and there was no mention of the provision of written information although this is not to say it wasn't provided. Providing written and verbal information regarding transfers has been shown to promote positive experiences for parents (Berube *et al.* 2014, Mitchell & Courtney 2005,) and has been found to be effective in reducing uncertainty (Bouvé *et al.* 1999, Coyle 2001, McKinney & Melby 2002). Therefore the provision of simple transfer leaflet as seen in Bouvé *et al.*'s (1999) study could have a positive impact on the parents' experiences and help to reduce some of their uncertainty. According to Berube *et al.* (2014) nurses can have a great influence on the process and outcomes of transfers by developing preventative interventions and strategies to reduce stress and anxiety although information should to be tailored to individual units. Hence one of the most clearly defined recommendations to emerge from this study is for information on transfers to be available and given to parents when they are admitted

to ICU. Prior to further contemplation on the facilitators and inhibitors experienced the final type of transition identified in this study is considered.

5.5.5 Developmental transitions

Section 4.1.4 titled 'Clawing every little bit back' revealed important findings of this research study associated with the developmental transitions experienced by the parents. Described under the sub-headings of 'Uncertain parenting' and 'Extraordinary parenting' the findings demonstrated how the role of the parents evolved over time progressing from initial turmoil and confusion to taking charge and becoming experts in the care of their technology-dependent child.

The concept of parents initially losing some of their parental role when children are admitted to hospital is not unique and has been described frequently in the literature (Ames *et al.* 2011, Coffey 2006, Flynn *et al.* 2013, Gibbons *et al.* 2014, Jerrett 1994, Meakins *et al.* 2015, Rempel *et al.* 2012, Shudy *et al.* 2006). Primarily due to their child's critical illness and requirement for I-LTV the parents in this study spoke of surrendering their parental independence to the professionals on ICU leaving some initially feeling disconnected from their child. Findings echoed in similar research regarding parents feeling disempowered particularly in ICU (Tong *et al.* 2009, Heaton *et al.* 2005, Carnevale *et al.* 2006). Participation in the day to day care of their child did not appear to be openly negotiated consequently there were unexpressed expectations and assumptions leading to parents being uncertain what they could do. Likewise these findings were similarly identified by Flynn *et al.* (2013) in their literature review of parents caring for children with a tracheostomy. Later as the children stabilised and the parents in this study began training to look after the supportive technology, they spent much of their time providing clinical care at the expense of the normal parenting duties with parents describing their role as a nurse as well as a parent, a theme previously captured by Kirk *et al.* (2005).

Whilst the findings in this study are unique to these parents, there are consistencies with other studies considering the experiences of caring for technology-dependent

children. These include the clinical caregiving role predominating the time the parents spent with their child (Kirk *et al.* 2005) and the priorities of the nurses sometimes devaluing the natural caregiving role of the parents (Manhas & Mitchell, 2012). When taking on the clinical role Kirk *et al.* (2005) defined it not only affects the relationship with the child but can alter the entire meaning of parenting and as they identified can have significant emotional and social impact on the parents. Furthermore, as articulated by Manhas & Mitchell (2012) parents also identified a blurring of boundaries in the nurses role as in addition to delivering clinical care they also carried out some of what parents perceived as their duties such as washing and dressing the children. Yet nurses didn't always appear to recognise the importance of depriving parents of this 'normal' parenting role, despite some parents clearly identifying this as an area of distress and potential conflict.

These findings support the work by Meleis *et al.* (2000) whose framework distinguished that there are a number of conditions that can influence transitions including personal, social and environmental factors. These conditions, recognised as facilitators and inhibitors can enable or constrain both the process and outcome of the transition (Meleis 2010) and some were found to have a significant impact on the parents' experiences.

5.5.6 Facilitators & Inhibitors

As recognised by Darbyshire (1994) inhibitors on the parent's role participation included feeling overwhelmed by the imposed power structure contained within the intensive care, the level of medical stability of their child, the length of time the child remained in hospital and relationships parents develop with the individual nursing staff on the various units. Initial deferment to the 'conferred authority' similarly recognised by Lindahl *et al.* (2011) showed most parents initially accepted the expertise and authority of the healthcare professionals but as the parents became more involved in their child's care they spoke of relationships with staff changing with some became disenchanted with the care and support provided a finding echoed by Shields *et al.* (2003b) who reviewed the needs of parents of hospitalised children.

Parents recognised how healthcare professionals acted as gatekeepers in determining how and when they were able to participate in caring for their child and what decisions they were allowed to make, findings also supported by Corlett & Twycross (2006) in their review of parental involvement in family-centred care. An important example of this, discussed previously under the heading of antecedents of uncertainty (5.4.1), raised the concept of 'ownership' and the argument recognised by Shields *et al.* (2003a) with regard to who 'owns' the child. As seen in this study and likewise in Flynn *et al.*'s (2013) literature review, as parents tried to develop some sort of normality and establish routines to regain a sense of involvement and control, there remained a perceived ownership by some of the staff. Consequently due to the nature of human-beings and the heightened sensitivity to the situation this meant that some individuals attached negative connotations to these situations as seen in section 4.1.4 which sometimes led to conflict. These findings are supported by Studdert *et al.* (2003b) who concluded conflict is common in patients who have a prolonged stay (> 8 days) in ICU with over a third of patients having conflict associated with their care. The experiences of difficult encounters described by the parents in this study share some congruence with Studdert *et al.*'s findings as there were some occasions when parents believed staff spoke to them in a discourteous manner and attributed this to the fact they had been in ICU for a long time. Although this study involved only a small sample the findings may have important implications for other families with children on I-LTV or other long-term conditions that require care on ICU for prolonged periods.

Additionally other studies have also shown nurses can experience problems when caring for patients who remain chronically ill but do not meet their expectations of requiring intensive care facilities (Coyne 2008, Stockwell 1972, Williams 2007). Although these studies did not involve children on I-LTV the findings share some resonance with those voiced by the parents in this current study. Descriptions in section 4.1.1 under the title 'Mixed Messages' suggested parents perceived that some ICU nurses developed negative attitudes towards them as they believed their children did not meet a genuine need to remain in intensive care. Although this was not

directly expressed, some parents understood their child to be '*too well*' to stay in ICU and felt some nurses believed they were using resources that could be utilised by more deserving patients. Similarly research has also found nurses can develop feelings of resentment towards those they believe are potentially blocking beds and denying the facility for other more appropriate patients (Williams 2007). This hostility, even when mild, can generate feelings of isolation and stress for the parents and can lead to mistrust of nursing and medical staff, findings that were described by some parents as their children's condition stabilised but they remained on ICU. These findings raise the possibility these long-term patients have the potential to be unpopular with health care professionals, a concept previously identified (Stockwell 1972, Kelly & May 1982, Lowbridge & Hayes 2013, Price 2013, and Williams 2007) and highlights ICU is an inappropriate place to care for children once they no longer medically require to be there.

Furthermore these experiences also share some congruence with the findings of Shudy *et al.* (2006) whose literature review on the impact of critical illness on families found parents received more support from healthcare professionals when the child's illness had life-threatening implications compared to families who had children with chronic but not life-threatening conditions. Support, or lack of it, can significantly affect the transition process (Al-Yateem & Docherty 2015) and can either positively contribute to the experience and help to facilitate progress or have a negative impact leading to adverse outcomes when there is an absence of such support (Meleis *et al.* 2000). A lack of support can also contribute to the uncertainty parents experience as they become unsure of who they can turn to provide emotional and psychological care (Latour *et al.* 2011). As seen in chapter four, the descriptions of the parents in this study established they received mixed support from healthcare professionals. They also voiced concerns regarding the level of emotional and psychological support offered during their child's admission. Whilst this study has focused on the descriptions of the parents and only represents their view of the time in hospital, personal experience and knowledge of the availability of professional psychological

and emotional support for these parents confirms that this is an area that is woefully lacking. Despite clear indication regarding the importance of psychological support in the service specification for LTV (NHS England E07/S/c) and Quality Standards for service providers of LTV (WMQRS 2015), too often this is an area which is neglected. Due to a lack of trained psychologists and current commissioning models of care, the psychological needs of families of critically ill children are not always met. The importance of emotional and psychological support is well known and as shown in other studies, professional support and involvement undoubtedly helps parents to cope with the stress and uncertainty experienced when a child is hospitalised (Al-Yateem & Docherty 2015, Jee *et al.* 2012, Melnyk *et al.* 2004, Rempel *et al.* 2012 Wigert *et al.* 2014)). Yet unlike the parents in the study by Melnyk *et al.* (2004) who benefitted from a structured interventional programme after their child had been admitted to PICU, the families in this study received no formal interventions to support them through the transition therefore, I would argue, this is an area where improvements need to be made.

Additionally evidence shows that positive collaborative relationships between healthcare providers and families are key components of family-centred care (Lerret *et al.* 2014), yet the findings demonstrated attitudes and personal interactions were not always supportive and at times parents had to negotiate their roles and fight for what they believed were their parental rights and duties. Some parents also found themselves caught in situations where they felt they had to support other parents who were experiencing negative attitudes towards them from some of the staff on the units. This not only added to the stress and anxiety at a time of uncertainty and insecurity but again demonstrates the lack of support which has been recognised as a critical element of supporting parents through the transition process (Ludin *et al.* 2011). Despite these inhibitory factors more positive and facilitative support was offered via the parental support groups and interaction with other parents whose children also had tracheostomies or were also on I-LTV. The parents spoke highly of the internet support groups and how they valued the strategies offered for coping and

resolving problems encountered by those new to the technology of I-LTV. As identified by Boyse *et al.* (2014) in their study of parents of children diagnosed with congenital adrenal hyperplasia, parents emphasised the importance of knowing and understanding the implications of their child's illness so they could begin to plan and imagine the future. Similarly the parents in this study wanted to understand their child's dependence on technology and what this would mean for family life thereby reducing some of the uncertainty. Therefore in accordance with other studies suggesting there may be considerable benefits for parental support groups to provide much needed support and information to parents new to the world of LTV (Lerret *et al.* 2014, Tong *et al.* 2009), these findings again showed congruence and confirmed the value of such vital support.

Meleis *et al.* (2000) identified 'interacting' and 'feeling connected' as two of the enabling factors in the transition process consequently a lack of connection and feeling isolated hinders the transition. Accordingly professional support during these 'rites of passage' is essential in helping parents adjust to their re-aligned world (Burden 1991). Therefore it is necessary for nurses to recognise these processes of transitions to be able to offer their support and assistance towards achieving healthier outcomes. Yet despite what appeared to be at times a lack of support as described by the parents, the findings of this study showed the parents successfully managed the transition process with clear demonstration of their newly developed skills and confidence in caring for the technology dependent child. The outcomes of transition described by Meleis *et al.* (2000) are 'mastery' and 'fluid integrative identities' both of which were demonstrated by the parents in this study and are now discussed.

5.5.7 Patterns of response – Process & Outcomes

Transition is a complex process of relearning and discovering new models (Kralik *et al.* 2006). Coyne's (2008) study of parental participation in the hospitalised child found parents initially uncertain in their role through the process of transition learnt new ways of being in the world and learned to cope with the changes in role identity. Likewise, in accordance with Coyne, as the parents in this study lived through periods

of adversity they demonstrated acceptance of their new world and gained knowledge, skills and strength which culminated in them developing new roles identities and achieving a level of mastery in caring for their technology dependent child. 'Mastery', defined as having comprehensive knowledge or skill in a particular subject or activity (Meakins *et al.* 2015) was demonstrated in abundance as the parents learnt new clinical skills to care for their children which were predominantly aimed at reducing the risk of untoward events occurring (Mishel & Sorenson, 1991). As seen in section 4.1.4 some parents quickly immersed themselves in the training to facilitate greater involvement however, others were more reluctant to become involved in the clinical tasks and required persuasion and support to begin training to provide the technical care. As recognised by Manhas & Mitchell (2012) developmental transitions can demand exceptional and extraordinary behaviours of parents requiring them to develop problem-focussed strategies to overcome the challenges of performing the complex clinical tasks. One such clinical task was to become an expert in the care of a tracheostomy (McNamara *et al.* 2009) and like other parents many were initially overwhelmed (Flynn *et al.* 2013). This increased level of responsibility left some parents feeling overburdened, with some acknowledging they required skilled professional help and support to enable them to successfully carry out their extended roles. Yet eventually almost all seemed to take it in their stride demonstrating the extraordinary parenting that often befalls parents of children with complex or critical illness (Snowden & Gottlieb 1989). Parents identified nurses' understanding and support through this transition was an essential element of their role transition and demonstrated how important it was for nurses to identify individuals who are struggling initially and also for them to recognise the process of transitions necessitate ongoing management. These study findings contribute further evidence to the knowledge of how important it is for nurses to understand the concept and process of transitions to ensure successful outcomes as seen by others (Darbyshire 2013, Kralik *et al.* 2006, Ludin *et al.* 2013, Rodriguez and King 2014).

Significantly as the parents' adjusted and their confidence with the technology grew, they became more competent and assured with their practice with many appearing to integrate it readily into their lives. One mother described the tracheostomy as part of her child's clothes and compared the suctioning of the tube to changing her child's nappy, signifying the changes becoming her new 'normal' as recognised by Mah *et al.* (2008). Yet for others the restriction it placed on their lives was at times overwhelming recognising they were unable to leave their child unaccompanied because of the fear the tracheostomy tube would become blocked or detached from the ventilator. These findings of fear and anxiety are consistent with other studies that have explored the experiences of caregivers living with a 'loved one' on I-LTV (Briscoe 2008) and therefore further exploration of the long-term consequences and effects of caring for a child on I-LTV are warranted.

During transition Gibbons *et al.* (2014) refers to caregivers losing sight of the future and their social connections whilst having to navigate uncertain and ambiguous illness trajectories prior to moving to a new 'normal' in which the caregiver's identity is re-established. This reconstruction of their parental identity was collectively described in this study as 'Extraordinary parenting'. This signified the transition from a familiar world prior to their child's admission, through a period of disruption and uncertainty, in to a world where without doubt some uncertainty remained but they began to adapt and live within their reconstructed lifeworld. Extraordinary parenting has previously described in other research involving parents of children with life-limiting or life-threatening conditions (Carnevale *et al.* 2006, Glendinning & Kirk 2000, Huang & Peng 2010, Mah *et al.* 2008, Ray 2002, Rempel & Harrison 2007, Rempel *et al.* 2012, Rodriguez and King 2014) and demonstrates how these parents like others developed resilience and multifaceted approaches to caring for their children. Individuals have also been reported to experience personal growth as an outcome of uncertainty (Lin *et al.* 2010, Madeo *et al.* 2012, Stewart & Mishel 2000) and this was seen through the parents' developmental transitions in the adoption of their new and extended parental roles and identities. Gibbons *et al.* (2014) also recognise parents can equally develop

new meaning and purpose in their lives and although this was not directly expressed during the interviews, it may be an area for further exploration. Overall the findings in section 4.1.4 demonstrated the parents' 'mastery' and 'fluid integrative identities' incorporating the dual roles of parent and nurse into their lives and taking on new responsibilities over and above those of normal parenting. Thus these findings correlate well with the research of Kirk *et al.* (2005) and the transition outcomes identified by Meleis *et al.* (2000).

In summary the parents in this study experienced multiple transitions in a world of complexity and change. The transitions were triggered by the onset of the child's illness and subsequent need for I-LTV and related to changes from a health-illness, situational, psycho-social and developmental nature. Transitions were extensive and far-reaching and impacted on numerous aspects of their lives. They also required the parents to make and accept major adaptations including relinquishing normal parenting roles prior to developing new knowledge and skills. This not only altered the dynamics of the family unit but also affected relationships between the parents, siblings and professionals involved in caring for the children. Whilst accommodating the intrusion of professionals delivering vital clinical care and taking over important aspects of their parental roles, the parents had to live for many months within an environment of inadequate facilities, devoid of home comforts and support they would normally receive. The parents described losing sight of what Burden (1991) termed their 'assumptive world' which contained thoughts and ideas of a future hoped and planned for. The parental accounts demonstrated being thrown into a world of chaos as the children became critically ill and a loss of familiarity with existing relationships and environment all of which Manhas & Mitchell (2012) distinguished as ubiquitous with transitions. This 'disconnectedness' one of the key characteristics of transitions (Chick & Meleis 1986) was echoed by the parents in this study as they spoke of their feelings of panic and anxiety and described their world falling apart. Furthermore the transitions experienced were dynamic and continual, with some presenting a never ending process. In accordance with Briscoe (2008) the parents in

this study confirmed patients commenced on I-LTV often have no clearly defined endpoint, acknowledging the ongoing nature and open-endedness of the transitions. Although this was incongruent with the early work of Chick & Meleis (1986) who initially maintained transitions involve a process and outcome with passage from one life phase to another it supports Meleis and colleagues later work identifying some transitions remain ongoing (Meleis *et al.* 2000). Over time and through the acquisition of new skills and regained confidence, they developed and progressed, eventually demonstrating outcomes of 'mastery' and 'fluid integrative identities' recognised by Meleis *et al.* (2000) as indicators of healthy transitions although their descriptions suggest better management of the transitions could have been facilitated .

The children's health-illness transitions also brought about numerous uncertainties for the parents. Despite wide recognition that life is generally acknowledged to be '*laden with multiple uncertainties that normally command little day to day attention in day-to-day life*' (Cohen 1995 p.63), the magnitude of uncertainty experienced by the parents in this study appeared to be intensified for a number of reasons. Initially there were uncertainties resulting from their child's critical illness and admission to hospital and ultimately intensive care and then subsequently as a consequence of the need for I-LTV. Further uncertainties were experienced by the parents as they transitioned through their journeys and came from multiple perspectives relating to existential, biographical, relational, environmental and temporal domains sometimes giving the parents hope and at other times causing them grief and despair. Overall this study has demonstrated the strong inter-relationship between transitions and uncertainty and revealed that during transitions there were many periods of uncertainty.

5.6 Links between Transitions and Uncertainty

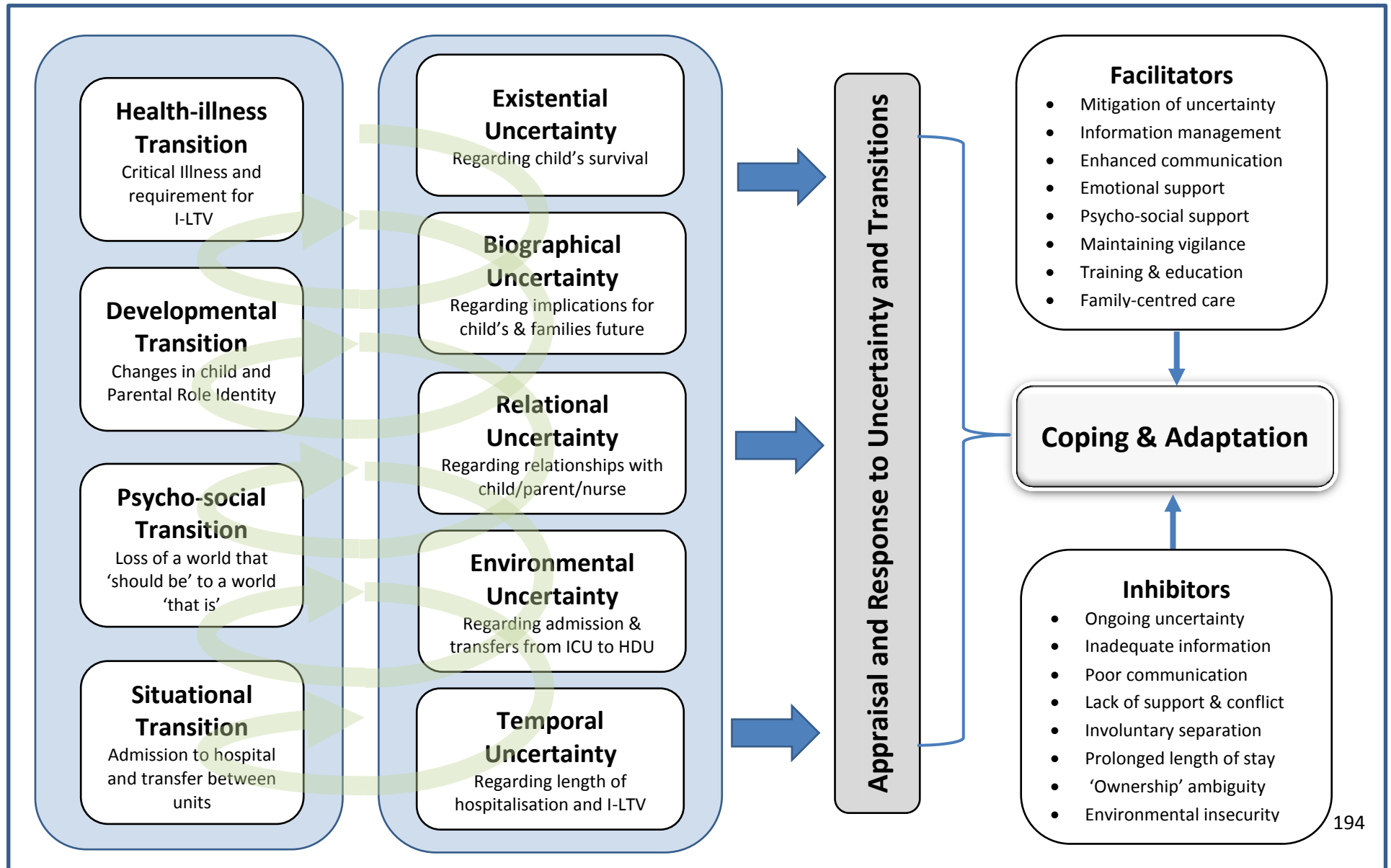
As a result of the findings and in keeping with the principles of hermeneutic phenomenology the theoretical work relating to the concepts of 'transitions' and 'uncertainty' revealed a wide volume of literature. From this review a number of theoretical frameworks underpinning the concepts of transitions and uncertainty were identified with Mishel's Uncertainty in Illness Theory (Mishel 1988) and Meleis's

Transitions Theory (Meleis *et al.* 2000) considered as being of particular relevance. Following in-depth hermeneutic analysis of the study findings both theoretical frameworks were used as an analytical lens to appraise the findings relating to the parents' experiences and accordingly it became apparent that the evidence from this study supported many aspects of the existing theory related to transitions and uncertainty. However, it also became apparent that a number of areas related to the parents' experiences had not been considered within the existing theories. Notably these included the psycho-social transitions and biographical and relational uncertainties experienced.

Furthermore despite the seemingly complementary relationship of the two theories, only one recently published paper on mobile health technology in chronic illness was found to discuss the use of both theories in relation to each other (Moore *et al.* 2015). Moore *et al.* (2015) recognised the benefits of combining these two theoretical frameworks stating Mishel's Uncertainty in Illness theory (1988) offered insight into the response of individuals thrown into a world of illness where they lack control, whereas the Meleis' Transitions theory was essential for inclusion as it addressed the process of change and adaptation. Similarly and regardless of the apparent lack of any other published literature to support the idea of linking these two theoretical frameworks, the decision to combine and progress elements of both theories was considered to be appropriate as the over-arching concepts and title of 'Transitions of uncertainty' epitomised the parents' journeys. Consequently a new framework based on combining the concepts of 'uncertainty' and 'transitions' together with the unique findings of this study was developed.

This new framework, shown in Figure 4, brings together these complex and multifaceted concepts and reflects the health-illness, psycho-social, developmental and situational transitions experienced by the parents, together with the dimensions of existential, biographical, environmental, relational and temporal uncertainty, arising as a consequence of their child's illness and need for I-LTV.

Figure 4: Framework of Transitions and Uncertainty based on the Parents' Lived Experiences



Although it could be argued that both Mishel's and Meleis theoretical frameworks are of particular relevance, viewed in isolation neither adequately addressed or identified the range of experiences described by the parents in this study. Significantly, by combining both concepts and incorporating the additional aspects of transitions and uncertainty, this newly developed framework goes some way towards capturing the 'lived experiences' of hospital for parents caring for children commenced on I-LTV. Consequently, this newly developed framework, seen in Figure 4, presents an original contribution to knowledge and constitutes some of the fulfilment required when completing a doctoral study.

It is also anticipated that this new framework will form the basis for healthcare professionals to consider and reflect upon the parental and wider family needs when caring for children commenced on I-LTV. The framework aims at providing a model for healthcare professionals to consider the experiences of parents' in the future and the individual journeys they may face and begins to provide evidence for new models and approaches to discharge planning. Specifically it aims to facilitate recognition and interpretation of parents' needs with respect to the origins of transitions and uncertainties and identifies some of the facilitators and inhibitors that can have an impact on parental coping and adaptation. Additionally it can be used to enable healthcare in helping parents to achieve the outcomes related to the psycho-social and role transitions required for their life at home with their technology-dependent child.

As such the new framework developed directly from the findings from this study not only considers the existential and biographical uncertainties regarding the immediate and longer term survival and outcomes for the child and family but also the associated environmental, relational and temporal aspects of their child's prolonged hospital admission. In addition it also identifies the transitions experienced by the parents triggered by the child's critical illness and subsequent need for I-LTV. By anticipating some of these uncertainties and recognising the nature of the transitions, professionals can help to reduce some of the stress and anxiety experienced by these parents. Furthermore it provides a model for nurses and healthcare professionals to

consider some of the nursing therapeutics that could be employed to support the families through this complex and prolonged journey.

Nursing therapeutics should be promotive, preventative and interventive (Schumacher & Meleis, 2000) and aimed at promoting and restoring the health and well-being for the child and family. Attention should be paid to identifying the vulnerable and critical points during the admission such as the transfer from ICU to HDU and supporting the parental role adaptation as they move from uncertain to extraordinary parenting developing mastery in their skills and caring. Accordingly this new framework can guide professionals towards these key areas for consideration and will provide a model for reflection on the complexity of the parents' journeys. Some of these key areas and clinical implications arising from the study will now be considered.

5.7 Implications for Clinical Practice

The aim of this study was to explore the lived experience of hospital for parents of children commenced on I-LTV. The findings of which revealed the concepts of 'uncertainty' and 'transitions' were common to all the parents during their time caring for their technology-dependent child. With more children surviving complex illness and increasing numbers going home on I-LTV the implications for clinical practice are of growing importance. Overall the study highlights the need to further develop healthcare professionals' knowledge and awareness on issues related to transition and uncertainty especially around support and communication for families. While existing literature on the theoretical frameworks to support the concepts of transitions and uncertainty provides valuable guidance and information the newly developed framework in Figure 4 provides an original contribution to knowledge and an alternative model for healthcare providers to consider the complex needs of these families.

Meleis *et al.* (2000) acknowledges much can be done to make transitions more successful and recently there has been heightened awareness and discussion of the broader concepts of transition in health and what can be done to improve the

transition process (Al-Yateem & Docherty, 2015, Berube *et al.* 2014, Kralik *et al.* 2006). Some of the recommendations to support coping and adaptation have been identified in chapter 5 and while specifically tailoring interventions to the needs of the individual have been found to strengthen effectiveness (Dy *et al.* 2015) there are clear recommendations regarding the benefits of preparing for transitions and improving communication in general (Al-Yateem & Docherty, 2015, Berube *et al.* 2014, Lopez *et al.* 2012). Furthermore what has become evident is that healthcare professionals need to be aware of and acknowledge the effect transitions have on parents and family members. Although there is a strong likelihood of individual variation and therefore it would be difficult for nurses to work with fixed routines and preparations, having knowledge and understanding of the transitions would equip nurses to provide an enhanced quality of care. Nurses are ideally placed to recognise when parents need additional support to cope with transitions thereby reducing the potential for the development of serious long-term implications which may impact on the whole family (Santacroce, 2003). Yet the findings from this study suggest the management of transitions requires further focus and improvement in a number of areas including during psycho-social, situational and developmental transitions.

Additionally, uncertainty has been recognised as an unavoidable characteristic of transition (Selder 1989) and of nursing practice (Vaismoradi *et al.* 2011). Therefore nurses require skills and knowledge on how to manage uncertainty effectively. As mitigation of uncertainty is not always possible additional responses to the management are required (Macnamara 2014). By exploring the main sources of uncertainty, such as the transfer between unit and the step down from ICU to HDU, healthcare professionals can try to resolve or reduce some of the uncertainties experienced. Nurses should also be cognisant of the individual's appraisal of uncertainty as resilience and tolerance of uncertainty have been found to be predictors of emotion focused coping (Macnamara 2014). Therefore when parents are struggling to cope, nurses can help to improve coping abilities by identifying ways

parents have previously coped effectively for example employing strategies such as taking one day at a time and creating small temporal milestones to aim towards.

This study also highlights children on I-LTV require healthcare professionals to recognise and support the different needs of the patient and family. Consequently this requires nurses to consider alternative models of care and some may require further training to enable them to be flexible in their approach to the long-term patient and family. In addition alternative models of service delivery need to be considered once the child is medically stable as this would help to address the ongoing problem of children on I-LTV occupying intensive care beds that could be utilised for other critically ill patients. Possible options include developing Transitional Care Units (TCU) or community in-reach teams providing trained carers working on a 1:1 basis and are one of a number of recommendations arising from this study.

As identified by Noyes *et al.* (2014) when children have complex health needs effective discharge planning is one of the seven critical success factors for a successful transition from hospital to home. Skilled nurse-led discharge, transparency and family-centred care are included as essential components amongst the key considerations yet the evidence from this study suggest that more needs to be done to improve this transition. An integral part of facilitating a child's transition to home is to manage the parents' expectations by setting realistic timescales and keeping them up to date regarding progress with discharge planning (Hewitt-Taylor, 2012), however this need did not appear to be achieved at all times. Effective and timely discharge planning for these complex patients should commence as soon as it is known that the child will be going home on I-LTV which is usually whilst they are on ICU. Therefore ICU nurses should refer children to the LTV team (where available) as soon as it is recognised the need for I-LTV so that the process can begin at the earliest opportunity. Whilst referring the child to the LTV team may give parents hope it should also be balanced with the recognition that due to the critical illness the child may not survive. Accordingly professionals working on ICU should consider all possible outcomes when supporting the parents which may include discussion and advance care planning

regarding end-of-life care decisions (Edwards *et al.* 2012, Provoost *et al.* 2006). Therefore planning for discharge or transfers need to be handled in a sensitive and timely manner (Green *et al.* 2015).

Due to the complexities of the discharge process for these children, the Department of Health's Continuing Care Framework (DH 2016) and NHS England LTV Service Specification (NHS England 2015, E07/S/c) recommends children on I-LTV should have a lead professional to coordinate care and communication. Tearl *et al.* (2006) recognise the advantages of having a dedicated discharge co-ordinator for these children including benefits for the patient, family and hospital multi-disciplinary team. Gunton-Bunn & McNee (2013) also strongly support the role of a key worker in providing information, emotional and psycho-logical support. However, the evidence from this study demonstrates this is an area for improvement, although it should be recognised that with the adoption of the standards recommended in the LTV Service Specification (NHS England 2015, E07/S/c) all providers of LTV should now be offering this support. Nationally there has been an increased emphasis on improving the discharge process to facilitate earlier and timelier discharges for these children and their families. The implications for these lengthy hospital admissions have been recognised from both the perspective of the child and family and also with respect to the restriction on critical care capacity (Neupane *et al.* 2014, Halley 2013, Noyes 2006). Practical aspects of discharge planning have been addressed with the development of frameworks to guide the transition from hospital to home (NHS England 2013, Noyes & Lewis 2005, Stephens 2005). Furthermore recent developments utilising an electronic pathway developed by the Children's Long-term Ventilation service at the Royal Brompton Hospital have been supported by NHS England and is now available in tertiary care centres across England to assist with the discharge process.

This study demonstrates it is not just about effective discharge planning but training, preparing and supporting the parents to cope with the adaptations and acquisition of new skills required to look after their technology-dependent child (Meleis 2010, Smith & Hilliard 2010). These study findings add to the evidence that professionals should

recognise and be prepared for the change in the parental roles as the desire for involvement and participation in decision-making increases (Fegran *et al.* 2008, Hummelinck & Pollock 2007, McGrath 2001). Professionals also possess the ability to discuss the changes in role, acknowledging the boundaries and how the parental role will change over time with the acquisition of new skills and knowledge, yet recognising there may be a tension between caring and parenting as initially their lives revolve around gaining experience with the technology. As evidenced in this study, the parents' perception was that healthcare professionals were focused on training parents in the complex medical needs of the child, but less attention was paid to the emotional and psycho-social needs of the child and wider family. In accordance with the findings of McGrath (2001) and Storgion & Stutts (2000) the focus of care was on the clinical needs of the child rather than the holistic needs of the child and family. Therefore providing children and their families with comprehensive, holistic family-centred care will enable parents better opportunity to successfully achieve 'mastery' and develop 'fluid integrative roles'. Thus the focus on clinical training needs should not be at the detriment of allowing the parents to have time and space to provide the 'normal' care-giving role.

Recognising parents as an integral member of the healthcare team may also enhance communication and provide a sense of involvement especially at times when they feel disconnected and unsure of their participation (Kepreotes *et al.* 2010). Effective communication as described by Roberts *et al.* (2015) is one of the six 'C's' central to the principles of nursing and is imperative when establishing positive therapeutic relationships with patients and their families. Moreover proactive communication strategies may be effective in reducing uncertainty, facilitating transitions and increasing parent's satisfaction (Khalaila 2014) and therefore deserve consideration by nurses involved in caring for these children and families.

Finally it is also important to consider the findings of this study in relation to the recent revisions to Nursing and Midwifery professional Code of practice (Nursing and Midwifery Council, 2015). Centred on the four key principles of prioritising people,

preserving safety, practising effectively, and promoting professionalism and trust, the Code sets out the professional standards of conduct and practice registered nurses and midwives working in the UK must uphold when providing care. As Meleis (2010) contends '*the most important raison d'être for nursing is the care of the patient*' and as most paediatric nurses would argue, the care of the parents is an essential component of this. Therefore the Code also applies to the care provided to the parents of children in hospital.

Some parents in this study described receiving excellent care during their child's admission in line with the NMC Code's standards, suggesting there are aspects of practice and care delivery that should be celebrated and shared. Parents welcomed environments that felt safe and hospitable and spoke of wanting to be involved with planning aspects of care for their children with the principles of family-centred care being at the core of services. Involving parents in training and education for healthcare professionals should also serve as a basis to guide the redesign of approaches to care. In line with the NHS Outcomes Framework (Department of Health 2015) and NMC Code (2015), prioritising and listening to the perspectives of parents will assist professionals to develop services focussed on providing safe and effective practice, and further develop services aimed at the enhancing quality of care, ensuring people have a positive experience of their time in hospital. These principles should form the basis for the recommendations for this study.

5.8 Recommendations

The recommendations of this study are based on the findings of the parents 'lived experiences' of hospital whilst caring for their child initiated on I-LTV. As acknowledged in the implications for clinical practice there are a number of specific recommendations arising from the main themes identified from the study and centre on the following areas:

1. As seen in the first main theme 'Going in to the Unknown' the parents described their experiences in relation to their child's critical illness and subsequent dependence

on technology. During this time they experienced a myriad of uncertainties and multiple transfers between hospital units, with care healthcare professionals adding to their stress and uncertainty as a result of inadequate and inconsistent communication. Therefore the first recommendation is for healthcare professionals to provide parents with consistent and effective communication regarding their child's clinical care and planning for discharge. This could be facilitated through the involvement of a key worker coordinating and supporting the parents throughout their time in hospital and their transitional journeys towards home. Additionally, utilisation of interventional strategies and discharge planning tools, with increased involvement of the parents, could enhance communication and reduce some of the uncertainties experienced. Furthermore exploration of the exclusion of parents from ICU ward rounds should be undertaken and challenged if found to be common practice in light of the recommendations of the Paediatric Intensive Care Standards (PICS 2010).

2. In helping to reduce the environmental and relational uncertainty experienced when transitioning between units, parents should be provided with consistent information relating to the transfers and in particular when their child is stepping-down from ICU to HDU. Information should be tailored to the individual needs of the family with planning and preparation for transfers beginning at the earliest opportunity. Preparation should include introducing parents to members of the HDU team and providing written and verbal information on what to expect regarding the lower dependency environment and the changes in staffing levels, all of which should take place prior to the transfer when at all possible.

3. Following the child being commenced on I-LTV, parents also indicated that much of their' stress and anxiety arose from the psycho-social transitions and uncertainty of what lay ahead as they feared for the life yet to come. As seen in the findings under 'Uncertain futures' there was little account of information being provided to them regarding what life would be like caring for a child on I-LTV at home. Accordingly, there is a requirement for healthcare professionals to develop information addressed at reducing the biographical uncertainty of the parents when faced with preparing to

take their technology-dependent child home. Healthcare providers should work jointly with parents to develop information that is available in a range of formats suited to the needs of the parents such as short films and DVD's. Additionally building up information and signposting resources, alerting them to useful guidance may enable them to find support from other parents and carers.

4. Parents also spoke of complex and emotional journeys encountered during their time in hospital with some indicating a lack of professional support whilst others described experiencing a degree of conflict with members of the clinical team. Most expressed a desire to be provided with improved emotional and psycho-social support for example through connections with other families who have been through similar experiences. This is an area nurses could proactively start to develop with the help of other parents who have been through similar experiences before them. Existing support networks should be explored which may lead to other sources of psycho-social support being considered such as connecting parents with other families and providing opportunities for them to meet in supportive environments. Professionals should also be cognisant of the anxiety and turmoil faced by the parents during this time of uncertainty and transitions and a review of available psychological support is recommended.

5. To address the uncertainties and anxieties experienced by the parents regarding their child's dependence on technology and need for constant supervision, consideration should be given to developing new or revised models of care that are delivered in an environment that helps to address the findings expressed within the main theme 'Safer at Home'. Whilst it was recognised by the parents that the 'taught vigilance' advocated by the clinicians was essential in helping to reduce the risks associated with caring for a child dependent on I-LTV, the parents struggled to adjust to the reduced level of care provided once the child was stepped down to HDU. Furthermore due to the prolonged lengths of stay most families had to endure multiple episodes of involuntary separation from their child. Consequently attention should be given to environments more suited to the needs of the medically stable child

such as step-down or transitional care units which could provide holistic family-centred care whilst the home-care package is being established and the parents are receiving training in how to care for their technology-dependent child.

6. In addition parents described experiencing complex transitions in their parental roles as indicated in the main theme 'Clawing every little bit back'. They initially perceived some of their parental role being taken away from them particularly when the child was on ICU. Yet as their child's condition stabilised the focus of their care was centred on the clinical training required to safely care for their technology-dependent child. Thus a further recommendation is for professionals to adopt a more family-centred care approach to looking after the needs of the children and their families. They should ensure they support the physical, emotional and psycho-social needs of the family in addition to facilitating the clinical training required to supporting the clinical needs of the child.

7. Based on the over-arching concepts of uncertainty and transitions emerging as the predominant features of parent's lived experiences, the final recommendation arising from this study is for professionals to be more aware of the complex needs of the family during these 'Transitions of Uncertainty'. Further testing of the new framework developed directly from the findings of this study shown in Figure 4 is recommended to assess whether it facilitates recognition and understanding of other parents' needs with respect to the origins of transitions and uncertainties when caring for a child commenced on I-LTV. It is anticipated this new framework will form the basis for healthcare professionals to consider and reflect upon the parental and wider family needs and will assist in providing evidence for new models and approaches to care. It may also be used to recognise and implement some of the facilitators that enable the parents to achieve healthier outcomes in relation to transitions and may be an area for future research.

5.9 Suggestions for further research

This study has highlighted a number of areas for future research as follows:

- Uncertainty relating to a child's chronic illness may be a risk factor for parents developing physical and psychological symptoms (Holm *et al.* 2008) and there are established links between parental hyper-vigilance and post-traumatic stress disorder (PTSD) (Santacroce, 2003). Therefore an area for future research is to explore whether the impact and consequences of I-LTV leads to changes in mothers' and fathers' mental health with longitudinal studies reviewing the implications of transition aiming to highlight specific issues pertaining to uncertainty and impact on parental coping. In addition as acknowledged by Berube *et al.* (2014) it is also important to explore the impact of vigilance on the child and siblings and the longer term outcomes on emotional function and family well-being.
- Although research has consistently demonstrated families are able to adapt and generally manage well with the uncertainties and changes associated with a child's illness with some demonstrating remarkable resilience and extraordinary coping (Cohen 1993, 1995, O'Brien 2001), there appears to be a lack of longer-term studies exploring the impact of I-LTV on family function and emotional well-being. Accordingly longitudinal studies are required to explore the experiences and outcomes of the parents' transitions and the impact of uncertainty on longer-term outcomes for the child and the family.
- A further area to consider is to review whether the implementation of interventional strategies such as providing simple written information prior to transfer as seen in the study by Bouvé *et al.* (1999) is successful for this group of children and parents. The stress and anxiety stemming from transfers between units was an area of concern for many of the parents in this study and has also been identified by van Manen (2010) as one of the areas that professionals take for granted especially when the move is perceived as

innocuous. Therefore there is also the potential to explore the transfers from the nurses' perspective in a comparative study.

- The findings from this study reflect that healthcare professionals frequently make unilateral judgements about children's treatment and care without fully involving the parents (Hallström & Elander 2005, Hummelinck & Pollock 2007, Gray *et al.* 2013, Lin *et al.* 2010). Although decision-making has been the subject of many research studies particularly when involving life-changing decisions related to aspects of their child's health, there has been limited exploration of the parents' involvement in the decision-making process regarding initiation of I-LTV. Although this study suggests parents were involved to some extent in the decisions to commence their children on I-LTV, whether all felt the discussions and decision-making were at an appropriate stage and made with sufficient support and information is unknown and therefore this is another possible area for future research. Also linked to this, is the concept of 'ownership' and the issues surrounding the parents perceived exclusion from the ward round. Further exploration in to these issues is recommended with particular regard to the long-term effects of prolonged hospitalisation on 'ownership' from both the parents' and professionals' perspective. In addition it may be pertinent to examine the impact of length of stay within the high dependency and intensive care settings and what effect this has on relationships between parents and hospital staff.
- Finally, exploring the lived experiences using a phenomenological approach always brings additional questions as the accuracy of the findings cannot be known as they are based on retrospective recall from individual perspectives. Nevertheless as Munhall (2012) describes, in phenomenological research we should not question the validity of the person we are trying to understand. With this in mind and the acknowledgement that this study involved participants from a limited area it is sufficient to suggest further observational studies are warranted to review whether the parent's experiences are reflected in other similar providers of healthcare.

5.10 Conclusion

Due to recent developments including increases in medical knowledge, the use of supportive technology and life sustaining treatments, more parents are living with the existential and biographical uncertainties of their children's survivorship which would once have been considered impossible (Santacroce 2003). With these advances in technology and a drive towards homecare provision, technology-dependent children are increasingly being discharged from hospital in to the care of their parents. With much of the previous research focusing on the complexities of discharging these children home the aim of this study was to explore the lived experiences of hospital for parents of children commenced on I-LTV. What this interpretive phenomenological study delivers is an in-depth understanding of the experiences of a small group of parents which can help to increase the sensitivity of healthcare professionals to the needs of the individual parents and families and guide future care and support to improve the time these children and their families remain in hospital whilst coming to terms with and preparing to take their child home on invasive long-term ventilation.

Using the philosophical approach based on tenets of hermeneutic phenomenology this thesis has presented in-depth findings and interpretation of the parents' experiences of their time spent in hospital caring for their invasively-ventilated child. Hermeneutic phenomenology was chosen as the research methodology as it is well suited to exploring the 'lived experience' of the individual from the perspective of those who experience it first-hand (Matua & Van Der Wal 2015). By adopting the approach based on interpretive phenomenology guided by the work of Heidegger (1962) and van Manen (1990), the study aimed to discover the hidden meaning and true essence associated with the parents' experiences of caring for their ventilator-dependent child in hospital. Heidegger's philosophy encourages the researcher's pre-conceptions and fore-knowledge as valid components of the research (McConnell-Henry *et al.* 2009b) collectively bringing together this fore-structure with the research findings producing a shared understanding of the phenomena in what Gadamer (1976) called a 'fusion of horizons'. Therefore based on my current knowledge and experience of caring for this

group of children and their parents it was considered that conducting the research based on the philosophical underpinnings of hermeneutic phenomenology held true to my intention to explore the 'life-world' of the parents involved in caring for their ventilator-dependent child. However, as Gadamer also concluded hermeneutics is an evolving process in which reaching a definitive interpretation is impossible (Annells 1999) therefore the interpretation reached in this thesis is only one understanding produced in recognition that many more are possible.

Using a modified approach of van Manen's (1990) framework for data analysis the lived experiences of the parents were explored. Throughout their child's hospitalisation the concepts of 'transition' and 'uncertainty' infiltrated the parent's experiences and became the over-arching themes of the study, therefore considering the impact of these became an important feature of this research. Gadamer (1976) understood hermeneutics to be a process of co-creation in which the researcher gains deeper understanding and new knowledge through a circle of reading, reflexivity and interpretation (Lavery 2003). By actively engaging in this process my intention was to uncover additional meaning and gain a deeper understanding of the parents' experiences. Consequently the findings were reviewed in relation to the theoretical frameworks around 'Transitions' (Meleis *et al.* 2000) and 'Uncertainty in Illness' (Mishel 1988, 1990).

Although Meleis *et al.*'s (2000) Transitions Theory presented an organised theoretical framework to consider the process and outcome of transitions it did not fully reflect the emotional, relational and developmental changes experienced by the parents. Similarly Mishel's (1988, 1990) theories relating to Uncertainty in Illness were found to give insufficient attention to transitions and wider parental issues. Therefore in accordance with findings of Murray & Mahoney (2012) regarding the importance of frameworks addressing all the needs of the family, it became important to develop a model that encompassed all the identified findings relating to the two concepts. In light of the findings an alternative model (Figure 4.) was developed to provide a framework for professionals to consider parent's experiences as understanding of the

phenomenon is integral to helping healthcare professionals support patients and their families through episodes of ill-health and hospitalisation (Colville *et al.* 2009). It is anticipated that this new model will be utilised by healthcare professionals to gain a deeper understanding of the uncertainties and transitions faced by the parents and will assist in the development of strategies to facilitate parental coping and adaptation. Furthermore being appreciative of the transitions and recognising the parent's response to changes is necessary to facilitate healthy transitions and can help to reduce the stress and anxiety they experience and help to restore a sense of normality (Lee & Rempel 2011).

Viewing transitions and uncertainty as both a process and outcome will afford healthcare professionals occasion to consider not only the end result, such as the eventual discharge, but the process in which the individuals are involved (Rempel *et al.* 2012). It also helps to identify those at risk from the more obvious perspective of the health-illness transition but also from situational and developmental perspectives. As Chick & Meleis (1986) suggest it can identify losses and gains that can be used to benefit others including parents involved in similar situations yet it should be remembered each situation is unique to the individual and generalisations must be viewed with caution. By recognising the concepts of transition and uncertainty in relation to this study it will help to facilitate the opportunity for healthcare professionals to better understand the experiences of parents and allow for discussion and training for future care to be considered in light of the findings and the recently revised NMC code of conduct for Nurses and Midwives (NMC, 2015).

Phenomenology is well suited to bringing insight to healthcare professionals who, as van Manen (2012) considered, may be unaware of or be insensitive to the experiences of the participants. In this case the participants were the parents whose children spend many months being cared for on the intensive care or high dependency units of the hospitals despite them being medically fit for discharge for a significant period of this time and in some cases more than six months. This study has illuminated a number of new and interesting aspects of caring for these highly dependent children and provides

further insight into the developing body of literature concerning the concepts of transitions and uncertainty and further advances the limited theoretical work on the concepts being used together. Inherent within the health-illness transition were the limitations imposed on the families due to the child's reliance on technology. Intertwined with the children recovering sufficiently to enable them to be discharge from hospital were the increased requirement for parental vigilance and clinical commitment over and above that of normal parenting. Similarly this lived paradox has been recognised by Briscoe (2008) and Heaton *et al.* (2005) who recognised the liberation gained from long-term ventilation also brought new physical and psycho-social restrictions for patients and their carers.

The findings also revealed the physical and emotional struggles encountered by the parents confirming the health-illness transition to I-LTV is a highly complex process as recognised by previous research (Briscoe 2008, Noyes *et al.* 2014) further acknowledging that transitions involve numerous sources of stress, where multiple needs exist (Al Yateem & Doherty, 2015). The transitions required parents to make profound adaptive changes as described by Boyse *et al.* (2014) and challenges were interspersed with losses which in themselves produced uncertainty & grief. They emphasised the need for healthcare professionals to gain an understanding of the parents' lived experience in order to recognise and begin to appreciate the complexities involved (Rodriguez & King 2009). As Schumacher & Meleis (1994) argue, nurses who have knowledge and experience of transitions are better able to support individuals through the process and can help to facilitate healthier transitions thereby assisting parents through difficult times.

The research endeavoured to promote an increased understanding of the emotional and transitional complexities experienced by parents whose children were commenced on I-LTV and highlighted short comings in a number of areas. It helped to support evidence that family-centred care was not truly practised especially when caring for children who remain in hospital long-term. Evidence also suggested that when the children improved and became medically well enough to be at home, professionals

sometimes forgot the needs of the parents and focused on the tasks of ensuring they were equipped and competent to deliver the clinical care needed once home. Whilst recognising this element of the preparation is essential to ensure the child is cared for safely, it seemed to be the focus for the parent's time with the child when in hospital to the extent the normal parenting roles and responsibilities are forgotten or perhaps not even considered. This study has shown there continues to be significant tensions and incongruities between the understandings of the parent and the healthcare professional which adds to the stress of the parents. As Darbyshire (1994) concludes parental participation is co-created between the parent and nurse yet what this study has identified is parents require more support and information to guide them through this difficult journey. New approaches to involving parents in planning their child's care are required through inclusive models delivered in care settings appropriate to the needs of the child and family such as Transitional Care Units (Kepreotes *et al.* 2010, Murphy 2008). As identified by Briscoe (2008) the period of time the child remains in hospital should be confined to when they medically need to be there.

In conclusion, this qualitative study explored the experiences of a small group of parents following their child's admission to hospital. All eight children had serious or life threatening conditions and as a consequence required admission to ICU and ultimately due to the critical nature of their condition required the supportive technology of I-LTV to facilitate recovery or to stabilise them medically. In spite of the complexity of the children's conditions all of them recovered sufficiently to be considered medically stable at the time of the interview. Some had already been discharged home whilst others were being cared for on the high dependency unit having been transferred from intensive care and were making good progress in their transition towards discharge.

In an atmosphere of openness and trust the parents shared their experiences of their time when their child remained in hospital. Although there were many times especially when the children were critically ill when the parents faced the possibility their child would not survive they were always, by nature of the situation, hoping and preparing

themselves that one day they would be able to take their child home. By openly sharing their experiences and 'Transitions of Uncertainty', they have helped to identify where further support is needed and where additional understanding is required by the healthcare professionals involved in caring for them regarding their needs.

In accordance with the understandings of Streubert & Carpenter (2011) this interpretive research study allowed the sometimes 'taken for granted' experiences of the parents to become more observable and comprehensible for others taking in to account the lived space, time, body and relational contexts of their daily lives in caring for their technology-dependent child in hospital. Matua & Van Der Wal (2015) recommend phenomenology as the ideal research approach for being able to verbalise the perceptions of the life experiences of individuals, as 'seen through their eyes'. It is able to elucidate the first-person experiences with first-hand accounts of phenomenon and in the context of this study, the parents' lived experiences of caring for their technology-dependent child in hospital. It is anticipated that in addition to this thesis providing an original contribution to existing knowledge it will also benefit both healthcare professionals and future parents when faced with the '*daunting*' prospect of their child being commenced on I-LTV.

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7 Appendices

7.1 Appendix 1: NRES Approval


Health Research Authority
NRES Committee East Midlands - Nottingham 1
The Old Chapel
Royal Standard Place
Nottingham
NG1 6FS
Telephone: 0115 8839695

20 March 2014

Mrs Melanie McFeeters

Study title:	A Qualitative Study Exploring the Lived Experiences of Parents Preparing to Take their Child Home on Invasive Long Term Ventilation (I-LTV)
REC reference:	14/EM/0097
IRAS project ID:	143567

The Research Ethics Committee reviewed the above application at the meeting held on 11 March 2014. Thank you for attending to discuss the application.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details, unless you expressly withhold permission to do so. Publication will be no earlier than three months from the date of this favourable opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to withhold permission to publish, please contact the REC Manager- Helen Wakefield on 0115 8839695.

Ethical opinion

The chair introduced himself and the committee and thanked you for attending the meeting.

The chair apologised to you for the mix up with times for attending the meeting. You acknowledged this.

The committee thanked you for an interesting worthwhile project.

The committee asked if you are part of the regular clinical care team. You confirmed that you are currently involved with the team but does not provide the hands on care to participants. You advised that you are involved in the multi-disciplinary meetings about the child. You confirmed that from April 2014, they will be no longer involved in the clinical care team as will be on a secondment post.

The committee asked you if parents are aware of the researcher in their clinical capacity, would parents be comfortable to discuss and express their opinions during the interview. You confirmed that parents are able to express their opinions freely and would initially ask the parents beforehand if they are happy to continue with the process.

The committee asked you to outline the recruitment process as this was unclear in the application. You advised that an invitation letter, participant information sheet will be sent out to potential participants as some children will have already been discharged, if the child is still on the ward parents will be given the same information pack and asked to complete a consent form on the ward. The committee advised you that parents should be given more than 24 hours to consent to be part of the study, you acknowledged this.

The committee asked you to outline the process of the pilot study questions. You advised the committee following the interview questions from the pilot study may change if they do not get sufficient information from the participants, the research team may explore some further issues to discuss or if parents raise specific points then this may be added to the set of questions. The committee advised that if any changes were being made following the pilot study then this should be reviewed as an amendment. You acknowledged this.

The committee asked you what support networks are in place for parents if they become distressed during the interviews. You advised that there currently is no provision for this support and if the child is still admitted to the hospital there is a six month waiting list for psychological support. If children have been discharged then the researcher would advise the parent to seek support from their own GP.

The committee asked you what the procedure will be if a child has died. You advised that they would have access to this information and would not contact the family thereafter.

The committee advised you to include information in the Participant Information Sheet stating the conditions under which confidentiality will be broke, such as the disclosure of unsafe practice, as this is only detailed in the IRAS application.

The committee advised you to advise participants that if they withdrawal from the study their data may still be used. You acknowledged this.

The committee advised you that there are a number of changes that are required in the Participant Information Sheet and this will be detailed in the decision letter. You acknowledged this.

You asked the committee if the points that had been raised at the proportionate review meeting had been reviewed at this meeting as part of the response. The committee confirmed the responses to the proportionate review had been reviewed alongside the full application.

The committee asked you if you had any further questions for the committee. You advised you do not. You thanked the committee for inviting them.

The members of the Committee present gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

Ethical review of research sites

NHS Sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

The Participant Information Sheet

1. "what is the purpose of this study" paragraph 3 – reverse 'on' and 'home'.
2. "what does the study involve" insert a sentence stating that the conditions under which confidentiality will be broken, such as the disclosure of unsafe practice .
3. "do you have to take part" make clear whether material will still be used in the analysis or not if the participant withdraws from the study.
4. "who has reviewed the study" insert Nottingham1 REC Committee.
5. Advise participants that the study is to be used to gain an educational qualification.

The Consent Form

1. Question 2 – advise participants that data obtained so far will be used or not.
2. Question 5 - Re-write to advise 'I understand that data collected during the study may be looked at by the researchers supervisor from De Montford University. I give permission for the supervisor to access my data.'

You should notify the REC in writing once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. The REC will acknowledge receipt and provide a final list of the approved documentation for the study, which can be made available to host organisations to facilitate their permission for the study. Failure to provide the final versions to the REC may cause delay in obtaining permissions.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non clinical trials this is not currently mandatory.

If a sponsor wishes to contest the need for registration they should contact Catherine Blewett (catherineblewett@nhs.net), the HRA does not, however, expect exceptions to be made. Guidance on where to register is provided within IRAS.

It is responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Approved documents

The documents reviewed and approved at the meeting were:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Evidence of insurance or indemnity		06 September 2013
Investigator CV	Melanie McFeeters	29 January 2014
Investigator CV	Judith Tanner	23 January 2014
Investigator CV	Rosemary Garratt	
Letter from Sponsor		20 January 2014
Letter of invitation to participant	1	11 September 2013
Other: DMU Approval		20 January 2014
Other: Annual Review		29 January 2014
Other: Registration letter		09 May 2013
Participant Consent Form	1	11 September 2013
Participant Information Sheet	1	11 September 2013
Protocol	2	04 November 2013
REC application	143567	29 January 2014

Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

Further information is available at National Research Ethics Service website > After Review

14/EM/0097	Please quote this number on all correspondence
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We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at <http://www.hra.nhs.uk/hra-training/>

With the Committee's best wishes for the success of this project.

Yours sincerely



Mr Robert Johnson
Chair

Email: NRESCcommittee.EastMidlands-Nottingham1@nhs.net

Enclosures: *List of names and professions of members who were present at the meeting and those who submitted written comments*
"After ethical review – guidance for researchers" SL-AR2

Copy to: *Martin Grootveld, De Montfort University*

7.2 Appendix 2: NRES Approval Confirmation



NRES Committee East Midlands - Nottingham 1
The Old Chapel
Royal Standard Place
Nottingham
NG1 6FS

Telephone: 0115 833695

25 March 2014

Mrs Melanie McFeeters

Dear Mrs McFeeters

Study title:	A Qualitative Study Exploring the Lived Experiences of Parents Preparing to Take their Child Home on Invasive Long Term Ventilation (I-LTV)
REC reference:	14/EM/0097
IRAS project ID:	143567

Thank you for your email of 25 March 2014. I can confirm the REC has received the documents listed below and that these comply with the approval conditions detailed in our letter dated 20 March 2014

Documents received

The documents received were as follows:

Document	Version	Date
Participant Consent Form	2.0	24 March 2014
Participant Information Sheet	2.0	24 March 2014

Approved documents

The final list of approved documentation for the study is therefore as follows:

Document	Version	Date
Evidence of insurance or indemnity		08 September 2013
Investigator CV	Melanie McFeeters	29 January 2014

Investigator CV	Judith Tanner	23 January 2014
Investigator CV	Rosemary Gerratt	
Letter from Sponsor		20 January 2014
Letter of invitation to participant	1	11 September 2013
Other: DMU Approval		20 January 2014
Other: Annual Review		29 January 2014
Other: Registration letter		09 May 2013
Other: Parents' Interview Schedule	1.0	11 September 2013
Participant Consent Form	2.0	24 March 2014
Participant Information Sheet	2.0	24 March 2014
Protocol	2	04 November 2013
REC application	143567	29 January 2014

You should ensure that the sponsor has a copy of the final documentation for the study. It is the sponsor's responsibility to ensure that the documentation is made available to R&D offices at all participating sites.

14/EM/0097

Please quote this number on all correspondence

Yours sincerely



Miss Helen Wakefield
REC Manager

E-mail: nrescommittee.eastmidlands-nottingham1@nhs.net

Copy to:



7.3 Appendix 3: NHS Trust R & D Approval

DIRECTORATE OF RESEARCH & DEVELOPMENT

Director:

Assistant Director:

Head of Research Operations:

31/03/2014

Mrs Melanie McFeeters

Dear Mrs Melanie McFeeters

Ref:

Title: A Qualitative Study Exploring the Lived Experiences of
Parents Preparing to Take their Child Home on Invasive
Long Term Ventilation (I-LTV)

Project Status: Project Approved

End Date: 02/09/2014

I am pleased to confirm that with effect from the date of this letter, the above study has Trust Research & Development permission to commence at

The research must be conducted in line with the Protocol and fulfil any contractual obligations agreed with the Sponsor. If you identify any issues during the course of your research that are likely to affect these obligations you must contact the R&D Office.

In order for the to comply with targets set by the Department of Health through the 'Plan for Growth', there is an expectation that the first patient will be recruited within 30 days of the date of this letter. If there is likely to be a problem achieving this target, please contact the office as soon as possible. You will be asked to provide the date of the first patient recruited in due course. In addition, the Title, REC Reference number, local target recruitment and actual recruitment for this study will be published on a quarterly basis on the external website.

All documents received by this office have been reviewed and form part of the approval. The documents received and approved are as follows:

Description	Version
Participant Consent Form	V2.0 Dated: 24 March 2014
Participant Information Sheet	V2.0 Dated: 24 March 2014
Letter of Invitation to participant	V1 Dated: 11 September 2013
Parents' Interview Schedule	V1.0 Dated: 11 September 2013
Protocol	V2 Dated: 04 November 2013
REC application	143567 Dated: 29 January 2014
Other: Annual Review	Date of Review Meeting: 15/01/2014 (Dated: 2012)
Other: Registration letter	Dated: 09 May 2013

Please be aware that any changes to these documents after approval may constitute an amendment. The process of approval for amendments should be followed. Failure to do so may invalidate the approval of the study at this trust.

Undertaking research in the NHS comes with a range of regulatory responsibilities. Please ensure that you and your research team are familiar with, and understand the roles and responsibilities both collectively and individually.

Documents listing the roles and responsibilities for all individuals involved in research can be found on the R&D pages of the Public Website. It is important that you familiarise yourself with the Standard Operating Procedures, Policies and all other relevant documents which can be located by visiting

The R&D Office is keen to support and facilitate research where ever possible. If you have any questions regarding this or other research you wish to undertake in the Trust, please contact this office. Our contact details are provided on the attached sheet.

We wish you every success with your research.

Yours sincerely

R&D Assistant Director
Encs: R&D Office Contact Information

7.4 Appendix 4: DMU Ethics Approval



HLS FREC Ref: 1207

18th December 2013

Melanie McFeeters

Dear Mel,

Re: Ethics application – Qualitative Study Exploring Parents Lived Experiences of Preparing to Take their Child Home on Invasive Long Term Ventilation (I-LTV) (DMU Ref 1207)

I am writing regarding your application for ethical approval for a research project titled to the above project. This project has been reviewed in accordance with the Operational Procedures for De Montfort University Faculty of Health and Life Sciences Research Ethics Committee. These procedures are available from the Faculty Research and Commercial Office upon your request.

I am pleased to inform you that ethical approval has been granted by Chair's Action for your application. This will be reported at the next Faculty Research Committee, which is being held on 30th January 2014.

Should there be any amendments to the research methods or persons involved with this project you must notify the Chair of the Faculty Research Ethics Committee immediately in writing. Serious or adverse events related to the conduct of the study need to be reported immediately to your Supervisor and the Chair of this Committee.

The Faculty Research Ethics Committee should be notified by e-mail to HLSFRO@dmu.ac.uk when your research project has been completed.

Yours sincerely,

A handwritten signature in black ink, appearing to read "M. Grootveld", written over a light blue horizontal line.

Professor Martin Grootveld
Chair
Faculty of Health and Life Sciences
Research Ethics Committee

7.5 Appendix 5: DMU Sponsor Confirmation



DMU HLS FREC Ref: 1207

20th January 2014

To whom it may concern;

RE: De Montfort University Ethical Approval: A Qualitative Study Exploring Parents Lived Experiences of Preparing to Take their Child Home on Invasive Long Term Ventilation (I-LTV) (DMU ref: 1207)

This is to confirm that De Montfort University is undertaking the responsibilities of Sponsor with regards to the above project, as outlined in the Department of Health Research Governance Framework (2005). Once a project is approved by De Montfort University's Research Ethics Committee, on the understanding that the protocol agreed by this institution is the same as that approved by the NHS ethics committee, it will be covered by the University's insurance. Providing that there is no deviation from the project specification approved by the University Ethics Committee I confirm that the University's Standard indemnity insurance will be provided.

We hereby confirm that we have in place a public liability and an employers' liability policy which covers our legal liabilities in respect of negligent acts or omissions which result in bodily injury to third parties and employees and/or third party property damage'. Cover applies in respect of this project but there is no provision for payment of "no fault compensation". Cover is otherwise subject to insurer's standard terms and conditions. The policy does not apply to medical treatment risks.

The project: 'A Qualitative Study Exploring Parents Lived Experiences of Preparing to Take their Child Home on Invasive Long Term Ventilation (I-LTV)' managed by Melanie McFeeters under supervision by members of staff from the Faculty has had ethical approval granted from the Faculty Ethics Committee. In addition, as part of the ethical process this project has also undergone independent academic scrutiny to ensure that the study content and design is appropriate to both the stated aims and objectives and to the level of study.

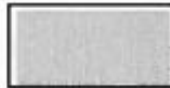
Should you have any questions regarding this, please do not hesitate to contact me.

Yours sincerely,

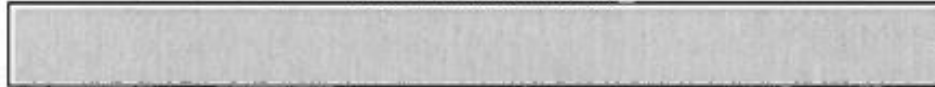
A handwritten signature in blue ink, appearing to read 'M. Grootveld', written over a light blue horizontal line.

Professor Martin Grootveld
Chair
Faculty of Health and Life Sciences
Faculty Research Ethics Committee
De Montfort University

7.6 Appendix 6: Research Working Agreement (DMU/NHS Trust)



RESEARCH AGREEMENT



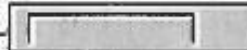
and

De Montfort University of the Gateway, Leicester LE1 9BH ("SPONSOR")

Re: A Qualitative Study Exploring Parents Lived Experiences of Preparing to Take their Child Home on Invasive Long Term Ventilation (I-LTV) ("Project")

(each a "Party" and together the "Parties")

Chief Investigator: Melanie McFeeters –




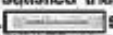


The purpose of this agreement is to formalise the rights and obligations of each Party including responsibilities for complying with applicable legislation.

RESEARCH GOVERNANCE TERMS AND CONDITIONS

By signing this agreement the Parties agree the following:-

1. Obligations

- 1.1 The Parties shall comply with all applicable laws and statutes relevant to the conduct of the Project, including the Human Rights Act 1998 and the Data Protection Act 1998, and with all relevant guidance including the ICH Guidelines on Good Clinical Practice, the NHS Research Governance Framework for Health and Social Care of April 2005 and the Medicines for Human Use (Clinical Trials) Regulations 2004, as amended from time to time.
- 1.2 The Sponsor's sole obligation under this agreement shall be to provide the services of De Montfort University (the "Supervisor") to supervise the activities of the Chief Investigator in conducting the Project in accordance with a project protocol approved by the Sponsor. The Sponsor undertakes to perform this obligation using reasonable care and skill. All warranties and undertakings not expressly set out in this agreement are hereby excluded to the fullest extent permitted by law.
- 1.3 Except as otherwise expressly set out in clause 1.2,  be responsible for the performance of all parts of the Project.
- 1.4  has copies of the following: a copy of the proposed informed consent form including electronic recruitment pack; a copy of the Chief Investigators CV; a copy of the application to the relevant Research Ethics Committee and ethics approval letter.
- 1.5 The Parties shall conduct the Project in accordance with:
 - the protocol including any amendments approved by the Sponsor;
 - the terms and conditions of the approval of the relevant ethics committee(s); and
 - the terms and conditions of the approval of the relevant NHS trust(s).
- 1.6  shall ensure that no research subject shall be recruited into the Project at the site of the Project until it is satisfied that all relevant ethics committee and NHS trust approvals have been obtained.  shall ensure that all such consents and approvals are maintained throughout the terms of the Project.

- 1.7 The Sponsor will promptly alert the R&D Manager (as notified to the Sponsor from time to time) at [] of any significant issues relating to the conduct of the Project that come to the Supervisor's attention.
- 1.8 [] is an NHS Health Trust and its involvement in this Project is covered by the NHS Clinical Negligence Scheme.
- 1.9 Nothing in this agreement shall limit or exclude the Sponsor's liability for: (a) death or personal injury caused by its negligence, or the negligence of its employees, agents or subcontractors; (b) fraud or fraudulent misrepresentation, or (c) breach of the terms implied by section 2 of the Supply of Goods and Services Act 1982 (title and quiet possession).
- 1.10 Subject to clause 1.9, (a) the Sponsor shall under no circumstances whatever be liable to [] whether in contract, tort (including negligence), breach of statutory duty, or otherwise, for any loss of profit, or any indirect or consequential loss arising under or in connection with the performance or contemplated performance of this agreement; and (b) the Sponsor's total liability to [] in respect of all other losses arising under or in connection with the performance or contemplated performance of this agreement, whether in contract, tort (including negligence), breach of statutory duty, or otherwise, shall in no circumstances exceed £50,000.

2. Monitoring

- 2.1 In the event that the Sponsor reasonably believes there has been any research misconduct in relation to the Project, [] will provide all reasonable assistance to any investigation into any alleged research misconduct undertaken by or on behalf of the Sponsor.
- 2.2 [] will make all reasonable efforts to supply documentation, information, records and reports as set out in the agreed protocol.

3. Termination

- 3.1 Either Party may terminate this agreement on one month's notice in writing to the other. Prior to so terminating this agreement, the terminating Party shall discuss with the other the reasons for wishing to terminate and, if both Parties think fit, explore alternative arrangements to termination.

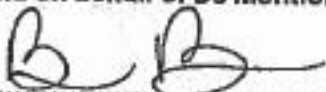
4. Publication

- 4.1 The Chief Investigator or the Sponsor, or both, shall following the completion of the Project be free to publish or otherwise disseminate the conclusions of the Project.

5. General

- 5.1 No variation of this agreement or the Project, including the introduction of any additional terms and conditions, shall be effective unless it is agreed in writing and signed by the Sponsor.
- 5.2 A person who is not a party to this agreement shall not have any rights to enforce its terms.
- 5.3 This agreement shall be governed by English law and the Parties hereby submit to the exclusive jurisdiction of the English courts.

Signed for and on behalf of De Montfort University

Signature:  Date: 28.3.14

Print Name: BEN BROWNE Title: CHIEF OPERATING OFFICER

Signed for and on behalf of

Signature:  Date: 31st March 2014

Print Name: Assistant Director of R & D Title:

7.7 Appendix 7: Research Invitation Letter



Title of Study: A Qualitative Study Exploring Parent's Lived Experiences of Preparing to take their Child Home on Invasive Long Term Ventilation

11th September 2013

Dear [Parent(s)]

I am currently undertaking a research study through De Montfort University and the [redacted] NHS Trust as part of a Doctorate in Health Science (DHSci). I would like to invite you take part in the study which we hope will provide us with information that will improve the experiences of parents and families when they are faced with taking a child home on invasive long term ventilation.

The title of the study is: A Qualitative Study Exploring Parent's Lived Experiences of Preparing to take their Child Home on Invasive Long Term Ventilation

To help you decide whether you would like to take part in this research study we have enclosed a parent information sheet that gives further information on why we are conducting this study and what the study involves.

We know that there are increasing numbers of children going home on long term ventilation and we hope that by listening to parent's that have already gone through or are currently going through the experience it will help to provide us with a better understanding of this difficult time and gather information that will enable us to develop ways to improve the hospital to home discharge pathway for all involved.

If after reading the parent information sheet you would like to take part in this important area of research or if you would like to ask any further details, please contact me either by phone or email on the contact details provided below.

Thank you for taking the time to read this letter of invitation.

Kind regards

Mei McFeeters

Tel: [redacted]

Email: [redacted]

LTV Research Invitation Letter Version 1.0, 11/09/13

7.8 Appendix 8: Participant Information Sheet

Page | 1



Title of Study: A Qualitative Study Exploring the Lived Experiences of Parent's Preparing to take their Child Home on Invasive Long Term Ventilation (I-LTV)

Name of Researcher: Melanie McFeeters

PARENT INFORMATION SHEET: 24/03/2014, V2.0

You are being invited to take part in a research study. This study is to be used to gain an educational qualification by the researcher (Melanie McFeeters) who is currently studying towards a Doctorate in Health Science (DHSci) at De Montfort University.

Before you decide if you would like to take part in the study, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. If there is anything that is not clear or you would like more information on, please feel free to ask. Thank you for reading this.

What is the purpose of this study?

Due to medical advances and increases in technology over the last few years, there has been a significant rise in the number of children going home on long term ventilation via a tracheostomy (this is also known as invasive long term ventilation or I-LTV).

We know that these children spend many months in hospital whilst the preparations and arrangements are put in place for families to care for their child safely at home. Whilst these preparations are complex and time consuming, most families feel that once their child is medically stable, the hospital is not the most appropriate place for them in the long term and that the family home is the best place for them and their families. However it is also recognised that the time these children spend in hospital can be difficult for the child, parent(s) and other family members.

To help us understand the difficulties and gather information from the parent's perspective, we would like to talk to parents about their experiences of preparing to take their child home on invasive long term ventilation. We are interested in hearing about the time from when it was decided that their child required invasive long term ventilation until the child was discharged home. We also plan to talk to some parents who are still in the process of preparing to take their child home whilst they are in hospital.

We hope that listening to parent's experiences will help to provide us with a better understanding of this difficult time and gather information that will enable us to develop ways to improve the hospital to home pathway.

LTV Research Parent Information Sheet (PIS) Version 2.0, 24/03/14

The aim of the study is to generate knowledge and information on both the positive and negative experiences of the families and explore whether parents feel that they are given sufficient information, choice and support throughout the time spent in the hospital setting to prepare them for looking after their technology dependent child in the home setting. It is anticipated that the findings of the study will build on existing knowledge and provide further information that could be used to improve the experiences of parents involved in the complex process encountered when taking a child home on I-LTV.

What does the study involve?

The study involves the researcher asking you about your experiences of your time in hospital and provides you with an opportunity to talk about your involvement in the discharge process and the feelings you experienced during the time spent preparing to take your child home.

The interview will last for up to 90 minutes and will be conducted by the researcher (Melanie McFeeters) at a time and place suitable to you which we anticipate will either be family home or the hospital if your child is still waiting to go home. We will ask for your permission to tape record the interview and we will ensure that all information that you give is kept confidential and that you cannot be identified on the transcripts of the interview. However, if during the course of the interview any details of unsafe practice are disclosed the researcher has a responsibility to inform a third party of these details and confidentiality may need to be broken.

Why have you been chosen?

There have been around 30 children within [redacted] region that have been commenced on invasive long term ventilation in the last three years. You have been chosen as a parent of one of these children. The research plans to invite all the parents who have taken children home (or are currently preparing to take children home) on invasive long term ventilation to be involved in the study and it is hoped that the researcher will be able to interview around twenty parents during the next six months.

Do you have to take part?

No, taking part is completely voluntary. It is up to you to decide whether to take part in the research study. You and your child will receive the same standard of care from the doctors, nurses and carers involved regardless of your participation. If you do decide to take part you are free to withdraw at any time without giving a reason. This will not affect the standard of care your child receives. Any material obtained during the course of the interview will be used in the research analysis unless the participant withdraws their consent.

What are the possible disadvantages and risks of taking part?

We do not think there are any disadvantages or risks in taking part, however it is recognised that talking about the time spent in hospital may be difficult for some parents and could bring back emotional memories of the challenging times and choices faced.

What are the possible benefits of taking part?

We hope that the information obtained from this research study will benefit other families and children requiring invasive long term ventilation in the future. It is hoped that the findings will provide clinicians with a better understanding of the experiences of parents in preparing to take these children home and that the information will provide a basis for further discussion and the development of information to support and improve the future care and management of these highly dependent children and their families.

What if something goes wrong?

If you have a concern about any aspect of this study, you should speak directly to Melanie McFeeters, [redacted], who is the lead investigator for the study. If this achieves no satisfactory outcome and you remain unhappy, you should then contact

the Administrator for the Faculty Research Ethics Committee who will direct your complaint to the Chair of the Ethics Committee or contact the NHS Complaints procedure at your local hospital. Contact details for the Administrator are as follows:

Tom Moore, Administrator for the Faculty REC, Research & Commercial Office, Faculty of Health & Life Sciences, De Montfort University, 1.25 Edith Murphy Building, The Gateway, Leicester, LE19BH.
Tel: 0116 2506122
Email: hlsfro@dmu.ac.uk

Details on the NHS Complaints procedure can be obtained from NHS Choices available at www.nhs.uk/choiceintheNHS/Rightsandpledges/complaints/Pages/NHScomplaints.aspx

Will my participation in this study be kept confidential?

All information collected during the course of the study is considered strictly confidential and will be kept on a password protected database. You will be given an ID code which will be used instead of your name and any identifiable information that you provide will be anonymised or removed.

What happens with the results of the research study?

Once the research is completed we aim to present the findings in a research report. All participants will receive a copy of the report but will not be identified in the report or any publications that may follow. It is anticipated that the findings will be presented at national and International respiratory meetings, and may be published in nursing and medical journals.

Who has reviewed the study?

The study has been reviewed by and received a favourable opinion from the Nottingham 1 REC Committee, the Ethics Committee of De Montfort University and the Research & Development Offices at [REDACTED]

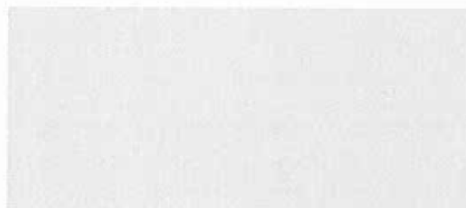
Contact for information

If you would have any questions or would like any further information regarding the study please contact Melanie McFeeters, [REDACTED]

For further information or independent advice on taking part in research projects, you can contact your local Patient Advice and Liaison Service (PALS) [REDACTED]

**THANK YOU FOR READING THIS INFORMATION SHEET.
WE HOPE YOU FOUND IT USEFUL.**

7.9 Appendix 9: Participant Consent Form



Title of Study: A Qualitative Study Exploring the Lived Experiences of Parent's Preparing to take their Child Home on Invasive Long Term Ventilation

Name of Researcher: Melanie McFeeters

Participant Consent Form: 24/03/2014, V2.0

**Please
Initial box**

1. I confirm that I have read and understand the information sheet dated 24/03/2014 (version 2.0) for the above study. I have had the opportunity to consider the information, ask questions and have these answered satisfactorily.	
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving a reason, and without my child's care or legal rights being affected. I understand that any data obtained during the course of the interview will be used in the research analysis.	
3. I agree to the interview being digitally audio recorded	
4. I agree for non-identifiable quotes to be included in the research report and in any publications arising from the research including journal articles and conference presentations	
5. I understand that data collected during the study may be looked at by the supervisor from De Montfort University. I give permission for the supervisor to access my data.	
6. I agree to take part in this study	

Name of Participant

Date

Signature

Name of Person taking consent

Date

Signature

Researcher Name

Date

Signature

DHSci LTV Consent Form Version 2.0, 24/03/14

7.10 Appendix 10: Interview Schedule



Title of Study: A Qualitative Study Exploring Parents Lived Experiences of Preparing to Take their Child Home on Invasive Long Term Ventilation (I-LTV)

Name of Researcher: Melanie McFeeters

Parents Interview Schedule Version 1.0, (11/09/2013)

Prior to the interview the researcher will check the parents understanding of the study and that they are still willing to participate. The researcher will gain verbal consent from the parent(s) and ask them to sign the consent form and agree that they are willing to have the interview recorded. They will be reminded that the interview will last for up to 90 minutes.

Interview questions:

'Thank you for agreeing to take part in this study. Over the next hour or so we would like to find out more about the time you spent in hospital with [insert child's name] from the time from when you first found out about them needing invasive long term ventilation until you took them home. We would like to hear about your experiences as a parent and the issues that you feel are important to tell us about preparing to take your child home from hospital. If at any time you feel or become upset and want to stop the interview either on a temporary or permanent basis please let me know. Are you happy to go ahead with the interview?'

- Where would you like to begin?
- What are your memories?
- What do you recall as being important to you at that time?

It is anticipated that during the interview there will be a need to further explore areas of interest with the parents and the researcher will use additional probing questions such as:

- Can you tell me more about that time?
- What were your feelings at that time?
- Can you describe how this made you feel?

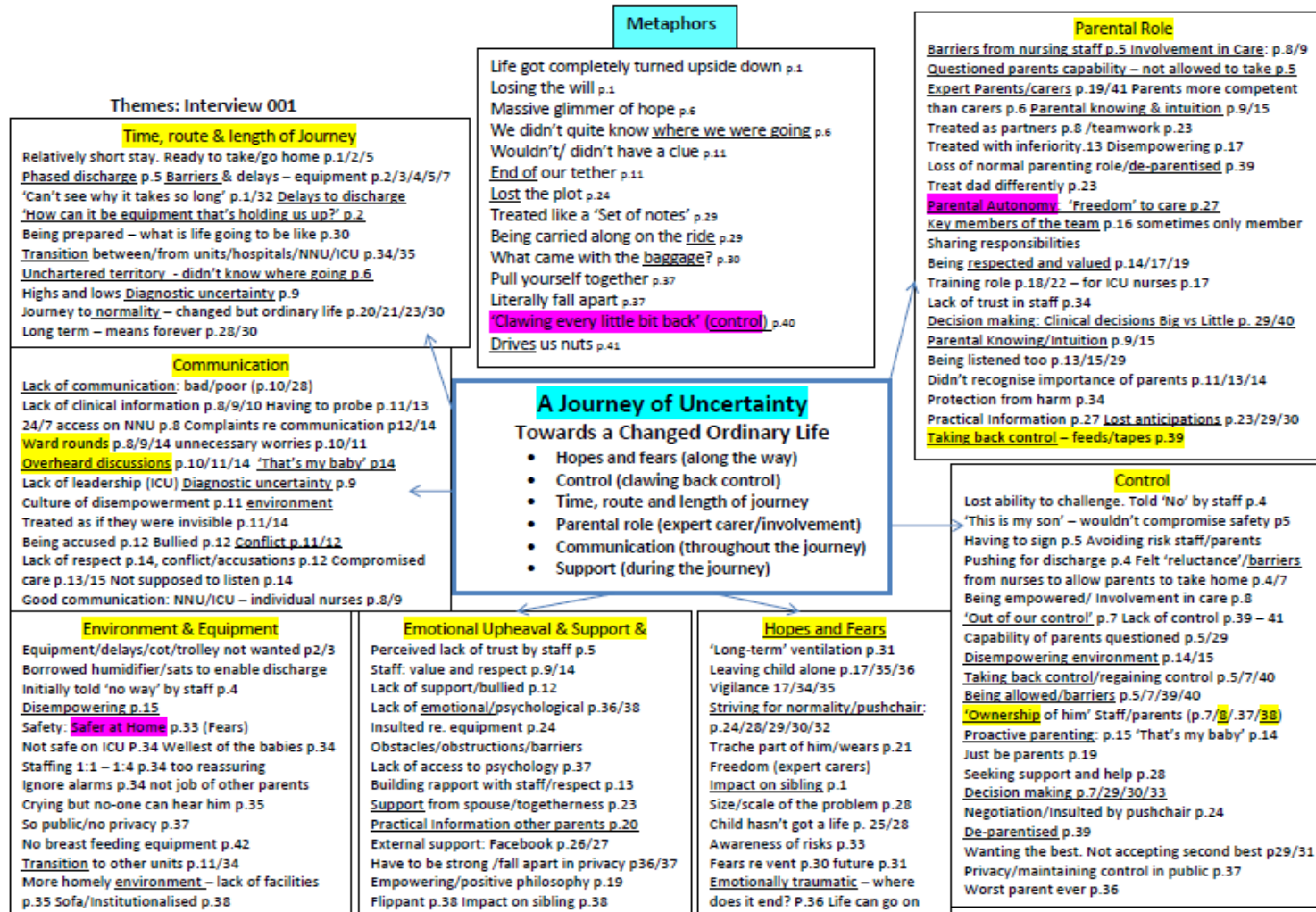
At the end of the interview the researcher will ask if there are any other issues that the parent would like to discuss by asking:

- As we have reached the end of the interview I would like to ask if there are any other issues or information that has not been mentioned that you feel as a parent you would like us or other parents in the future to know.

Thank you very much for your time and sharing your experiences of the time you spent in hospital preparing to take [insert child's name] home. The interview is now complete.

LTV Research Interview Schedule Version 1.0 (11/09/2013)

7.11 Appendix 11: Example of Thematic Map Analysis of Interview 001



7.12 Appendix 12: Example of Thematic Summary: Theme 1 ‘Going into the Unknown’

<ul style="list-style-type: none"> • ‘Going in to the unknown’ (Transition & change) 	<ul style="list-style-type: none"> • Uncharted territory – no map no guide 	<u>Admission to Critical Care/NNU</u>	<p>Scared (004 p.1/3) Petrified/scared (005 p.11/12) Scared about everything (006 p.1/4) Had to just sit there and watch the ambulance go away (006 p.5) Being alone vs. always people around (007 p.11) Lack of privacy – needed to have time out – away from stress and noise of alarms (007 p.12) ‘Just 10 mins on your own’ (007 p.13) So public/Lack of Privacy (001 p.37, 003 p.10/30, 004 p.2, 006 p.7) Kicked out the bedrooms/ICU tried to get me out (004 p.14) Inadequate facilities (001 p.38, 003 p.30, 004 p.2/13) Ward/Unit <u>was like a home</u> – we lived there, moved in there (004 p.13) More homely environment – lack of facilities/sofa (001 p.35, 003 p.30) Awful sofa bed/nowhere to sleep (006 p.6) Lack of facilities for parents/siblings (007 p.17) Exposure to bad things/distress/emergencies/alarms (004 p.1/2) Hospitalised/hospital bubble/parents medicalised/all the child had ever known (006 p.11/16) Became institutionalised (001 p.38) Introduction to the units – clarification on ground rules and boundaries (007 p.10) Pressure on HDU/no pressure on NNU (007 p.16) Dr’s more accessible on NNU (007 p.15/16) better on NNU (007 p.16) Wanting the best (001 p. 29/31, 002 p.3) Massive glimmer <u>of hope</u> (001 p.6) Won’t make the journey – die trying to save her (002 p.5) Fearing the worst (002 p.5, 003 p.14) Every anaesthetist worst nightmare. No guarantees (002 p. 5) Fears - Leaving child alone (001 p.35/36, 003 p.2) Tracheostomy hit hard/permanent (003 p.5, 004 p.3, 005 p.8, 008) Milestones reached – <u>gave hope</u> (003 p.14) Convinced he would be ok initially post ECMO ‘doing really well’ (005 p.1) Hoped could do it without the trache (005 p.1)</p>
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7.13 Appendix 13: Summary of Thematic Analysis

Main Themes	Sub Themes	Keywords, Notes and Quotes
1. 'Going into the Unknown'	<ul style="list-style-type: none"> Uncharted territory 	<ul style="list-style-type: none"> - Admission to Critical Care/NICU - Lost anticipations of parenting - Diagnostic uncertainty 'I don't like that one' - 'Sat on a Rollercoaster' (Emotional turmoil) - Transfers (Unexpected differences) - 'Daunting' & 'having to start afresh' - Stepping down from ICU to HDU
	<ul style="list-style-type: none"> Mixed messages 	<ul style="list-style-type: none"> - Clinical Information - Inconsistent & Contradictory Information - Overheard Conversations - Conflict
2. 'This wasn't what we wanted'	<ul style="list-style-type: none"> Uncertain futures 	<ul style="list-style-type: none"> - Future hopes and concerns - Impact on Family & social implications - Resilience & Coping strategies - Phased Discharge. 'Why does it take so long?' (Transition to Home) - Barriers and Delays to discharge
	<ul style="list-style-type: none"> Information & Signposting 	<ul style="list-style-type: none"> - Internal support – Family, friends, HCP - External support – Facebook, other parents - DVD's
3. 'Safer at Home'	<ul style="list-style-type: none"> Vigilance 	<ul style="list-style-type: none"> - Precarious survival - Taught vigilance - Reduced staffing levels - 'Too well for ICU' - Overstepping boundaries
	<ul style="list-style-type: none"> Involuntary separation 	<ul style="list-style-type: none"> - Isolation - Security on the units - Ward rounds - Dividing time & loyalties - Worst parent ever
4. 'Clawing every little bit back' (Parental Role Transition)	<ul style="list-style-type: none"> Uncertain Parenting 	<ul style="list-style-type: none"> - Disempowering environment & culture - Role ambiguity & 'Ownership' - De-parentised – changes in role identity - Decision making - Conflict Staff/parent Relationships - Resilience and coping strategies - Psychological support
	<ul style="list-style-type: none"> Extraordinary Parenting 	<ul style="list-style-type: none"> - Taking back control - Expert carers - Freedom to care - Parental Knowing & Intuition - Negotiated Partnerships - Striving for normality

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